Head and neck 1st consultation – Stakeholder comments

30 January – 27 February 2004

National Institute for Clinical Excellence

Organisation	Section number	Comments Please insert each new comment in a new row.	Developers' response Please respond to each comment
Abbott Laboratories Limited (BASF/Knoll)	2	Although dietitians are mentioned in the listing of MDT members (starting on page 42), their responsibilities are not described in the section starting on page 46. The Dietitian in the team (p43) should have expertise in nutritional support as well as having a special interest in those patients with head and neck cancer.	A paragraph on the role of the dietitian has been added.
Abbott Laboratories Limited (BASF/Knoll)	Pg 44	No mention of gastoenterologists/surgeons in the extended MDT (p44) who may be required for PEG or other enteral feeding tube placement.	The following text has been added in the section on extended team members: 'Gastroenterologists, radiologists and GI surgeons for PEG or other enteral feeding tube placement and support.' A bullet point has been added, reading as follows: 'Gastroenterologists, radiologists and surgeons with expertise in gastrostomy creation, feeding tube placement and support for patients who require tube feeding.'
Abbott Laboratories Limited (BASF/Knoll)		The responsibilities of the Dietitian should be described on page 48 e.g. Malnutrition and eating difficulties are common in patients with head and neck cancer. Many require nutritional supplementation or tube feeding both in hospital and at home. The Dietitian should be involved in assessing the nutritional status of the patient before treatment begins, and should be responsible for managing their nutritional care throughout the treatment course. The Dietitian and SALT should work together to manage eating and drinking problems. (The role of the Dietitian is described on p70-71 but should also be included as part of the MDT roles)	The description of role of the dietitian has now been expanded, and this point is now clear.
Abbott Laboratories Limited (BASF/Knoll)	4	The section on nutritional assessment on page 73 discusses the results of several studies, but they are not referenced. The same is true of the sections on dental assessment, psychological intervention and preparation for laryngectomy. All references from number 72 onwards will need to be renumbered.	This comment is understandable in the absence of the formal Evidence Review. For the next phase of consultation and in the published version the Evidence Review will act as a companion document and contains the material required.
Abbott Laboratories	5	The sections on UAT cancers, choice of treatment modality (page 84), radiotherapy, chemoradiation and chemotherapy, prophylaxis	The Evidence Review will be available for the next consultation. This is the document that sets out the

Limited (BASF/Knoll)		for oral mucositis, nutritional support and dietary supervision and relaxation therapy (page 89) are not referenced.	evidence in a systematic and comprehensive manner.
Abbott Laboratories Limited (BASF/Knoll)	General	An 'Abbreviations/Glossary' section would be helpful.	This will be provided for the second consultation.
Afiya Trust, The			This organisation was approached but did not respond.
All Wales Head and Neck Cancer Steering Group			This organisation was approached but did not respond.
Amgen UK Ltd			This organisation was approached but did not respond.
Association of British Neurologists	Pages 31/32	It is suggested that urgent referrals to the Lead for head and neck cancer MDT should include presentations of cranial neuropathies and orbital masses. We consider that most often these two presentations will not be related to head and neck cancer, and that the former will require input from a neurologist and the latter input from an ophthalmologist. WE suggest that such a referral process is added at this stage or alternatively a comment is made such as "the lead clinician should liaise closely with the local neurologist / oththalmologist in these situations".	The urgent referral criteria are taken verbatim from the DH criteria. These are currently being revised by NICE.
Association of British Neurologists	Page 44	We suggest that neurologist is added to the list.	The list originally included neurosurgeon (now 'specialist surgeons'); what would be the rationale for including a neurologist?
Association of Hospice and Specialist Palliative Care Social Workers			This organisation was approached but did not respond.
Association of Surgeons of Great Britain and Ireland			This organisation was approached but did not respond.
Association of the British Pharmaceuticals Industry			This organisation was approached but did not respond.

(ABPI)			
AstraZeneca UK Ltd			This organisation was approached but did not respond.
Aventis Pharma			This organisation was approached but did not respond.
Bard Limited			This organisation was approached but did not respond.
Baxter Oncology			This organisation was approached but did not respond.
Bayer PLC			This organisation was approached but did not respond.
Biolitec Pharma Ltd (formerly QuantaNova Limited)	General	The use of photodynamic therapy (PDT) as a treatment option for recurrent and advanced disease is not adequately covered by the provisional guidance. The clinical effectiveness of PDT in recurrent and advanced head and neck cancer has been demonstrated in clinical trials (D'Cruz AK, et al. Head Neck 2004; in press; http://www3.interscience.wiley.com/cgi-bin/jissue/89011929. The data described in this paper formed the basis for approval in the European Union for the use of Foscan-mediated PDT in the palliative treatment of patients with advanced head and neck squamous cell carcinoma failing prior therapies and unsuitable for radiotherapy, surgery or systemic chemotherapy. This paper and supporting trial report were submitted to the guidance group within the Biolitec Pharma submission document. In addition, the data regarding the cost-effectiveness of PDT in this indication have been published (Hopper C, et al. Oral Oncol 2004; 40; 372-382. We believe that the benefits of this therapeutic option are not adequately covered by the provisional guidance.	The Editorial Board has discussed this issue again, and is of the view that there is no rationale for more detail to be included on PDT. The text on 'other treatment modalities' has now been moved to the section on recurrent and advanced disease.
Biolitec Pharma Ltd (formerly QuantaNova	6.A.	There is no reference to the use of photodynamic therapy for recurrent and advanced disease.	Specific reference to PDT is now made in this section.

Limited)		The existing statement in paragraph 3, line 2, under "UAT cancers" could be amended to read: "Chemotherapy, chemoradiation or photodynamic therapy may be appropriate for some patients."	
Biolitec Pharma Ltd (formerly QuantaNova Limited)	6.D.	There is no reference to the availability of photodynamic therapy for patients with recurrent or advanced disease (as there is for surgery, chemoradiation and radiotherapy for primary disease, page 92). A bullet could be added under "Structure" to read: "Facilities for provision of photodynamic therapy".	Specific reference to PDT is now made in this section. PDT is only recommended in the context of trials, so not appropriate to include.
Biolitec Pharma Ltd (formerly QuantaNova Limited)	7.A.	There is no reference to the use of photodynamic therapy for palliation. The existing statement in paragraph 4, line 1, under "Recommendations" could be amended to read: "Surgery, radiotherapy, chemotherapy and photodynamic therapy can all be used for palliation, and all treatments should be available".	Reference to PDT is made in the section on recurrent disease.
Boehringer Ingelheim Ltd			This organisation was approached but did not respond.
Brighton & Sussex University Hospitals Trust			This organisation was approached but did not respond.
British Association for Counselling and Psychotherapy	General	BACP welcomes the emphasis placed on the need for a holistic approach to the treatment of people with head and neck cancers. The guidance manual clearly shows that the importance of emotional support for patients has been fully considered.	No response required.
British Association for Counselling and Psychotherapy	1.	The last sentence of the third paragraph (p.34); 'Primary care staff should take advantage of any opportunities for counselling patients, explain that they can reduce the risk of cancer by quitting, and offer help with overcoming addition' should be changed to read: 'Primary care staff should take advantage of any opportunities for encouraging patients to reduce their risk of developing cancer by overcoming addiction, and offer to refer them onto appropriate	This wording has now been substantially revised.

		counselling/addiction services or patient support groups where appropriate.'	
British Association for Counselling and Psychotherapy	3.	Although it is important to include a counsellor as an extended team member of the multidisciplinary team (MDT), we are concerned that a 'bereavement counsellor' is identified. This is a more specialist counselling role that may not be appropriate in all circumstances, especially if cancers are identified early on and life-saving treatment is provided. We would suggest that access to a variety of different counselling specialisms is available.	Agreed. This reference has been deleted.
British Association for Counselling and Psychotherapy	3.	The last sentence of the second paragraph (p.48) implies that CBT should be the primary choice of therapy made by MDT extended team members. Although BACP supports the practice of CBT it is not always the best choice of therapy. CBT aims to help a patient modify their behaviour to their benefit, whereas other counselling modalities, such as person-centred therapy, offer empathetic support which may be more appropriate depending on the patient and type/extent of the cancer. We would therefore recommend that the sentence be rewritten to avoid any assumptions being made.	This specific reference has been removed.
British Association for Counselling and Psychotherapy	4.	The last paragraph (p76) discusses a focus group study with patients in England which found that many patients felt that counselling did not help 'usually because the counsellors had not listened to them but rather, tried to find solutions to their problems'. This highlights the potential difference in counselling modalities (see point made about counselling specialisms above). As the study is not referenced, we are unable to ascertain any details. We would suggest that the paragraph be rewritten to provide reference for further analysis. We suggest reference is made to the type of counselling reviewed by the focus group study and that listening and supportive counselling is recommended here.	The reference is to Edwards, D 1999. Full details, and the reference of the study are included in the Research Evidence, available at the second consultation.
British Association for Counselling and Psychotherapy	8.	Sixth bullet point ''Psycho-oncology, liaison psychiatry or clinical psychological services' should include Counsellors/ Psychotherapists, in-line with recommendations both earlier in this manual, and in the NICE Guidance on supportive and palliative care for people with cancer.	Psychological service support is already adequately covered. Please cross-reference with the generic NICE guidance for more detail.

British Association for Counselling and Psychotherapy	8.	Last paragraph, first sentence (p.106) should read; 'Social skills training and counselling/CBT should be available for patients who have problems with social anxiety after treatment.	No amendment proposed.
British Society for Oral and Maxillofacial Pathology	General	A number of readers felt that the report was badly constructed, with quite a lot of repetition between sections and some contradictions. Overall it was felt that the guidelines were not clear, and that to some extent, the report detailed current practice. Unfortunately the evidence quoted suggests that good practice is not widespread and rarely applied fully.	There has been considerable re-drafting for the second consultation version. Wherever available, appropriate evidence is quoted; unfortunately, there are a number of areas where there is no evidence.
British Society for Oral and Maxillofacial Pathology	P26	The report alludes to a 'national advisory group' on oral cancer screening. If this refers to the UK working group report of 1992, the full reference should be given. The conclusions quoted are also wrong. The UK working group could not recommend population screening for the following reasons: Oral cancer is relatively rare The natural history of oral cancer is poorly understood There is insufficient data on cost effectiveness or effectiveness of different possible screening scenarios More research is needed particularly in high risk and opportunistic screening.	The following text has now been inserted, which deals with this point: 'There is no national screening programme for any form of head and neck cancer and it is unlikely that such a programme will be established in the near future. Reasons for this include the following: First, although screening has been considered for oral cancer, this is relatively rare so the pick-up rate would be very low. Second, the natural history of these cancers is poorly understood. Finally – and crucially – there is no evidence to show that such screening would be beneficial for the population as a whole. More research is needed, particularly on screening members of high risk groups and opportunistic screening'.
British Society for Oral and Maxillofacial Pathology	P26	The report states that a definitive diagnosis requires a FNAC or a biopsy. This is wrong. The gold standard for diagnosis is a tissue biopsy. FNAC has a limited role in the assessment of lumps in the neck and should only be applied in centres where the relevant facilities and expertise are available. Primary lesions require open biopsy	See response to point 4 below.
British Society for Oral and Maxillofacial Pathology	General	There tends to be an overemphasis on FNAC. Although ideal for the assessment of lumps (and salivary tumours) it is only really useful where specialist facilities exist – ie. Clinicians or pathologists experienced in the technique and an expert cytopathologist. Such centres are rare. Experience tells us that many FNAs are taken by inexperienced clinicians and reported by pathologists without specialist training. This has lead to very low	The developers feel that FNAC is crucial in determining the nature of the tumour. The issue is therefore about moving towards provision of this expertise. The new draft acknowledges that this may take some time to achieve, and that interim arrangements may be necessary. The revised text reads as follows: 'Patients with neck lumps or suspected salivary gland

		sensitivities and many inadequate samples. This is a disservice to patients and the report should be aware that where special centres do not exist, open or core biopsies may be better. In breast cancer, FNAs are increasingly being replaced by core biopsies for this very reason. It should be noted that these issues are alluded to on page 61 of the report.	tumours should be referred to specialist lump clinics for investigation. Any patient with an isolated neck lump should first be examined by flexible endoscopy. There should be an experienced on-site cytologist who can provide FNAC in the clinic to determine the nature of neck lumps. This may take some time to achieve and interim arrangements may be necessary.'
British Society for Oral and Maxillofacial Pathology	P31	The report states that patients meeting the '2 week-wait' criteria should be referred direct to the lead clinician. (also mentioned on P34) The authors should be aware of the number of cases this will generate. A recent study shows that 4.2% of patients attending the dentist may have a referable lesion (LIM K, MOLES DR, DOWNER MC, SPEIGHT PM (2003) Opportunistic screening for oral cancer and precancer in general dental practice: results of a demonstration study. *Br Dent J,* 194, 497-502). Many of these cases are suspicious lesions or precancers (white or red patches) which are often managed by specialists in Oral Medicine.	This will ensure the best outcome for the patient. The text as written does not preclude a specialist in oral medicine from undertaking this activity.
British Society for Oral and Maxillofacial Pathology	General	The report does not give due recognition to specialists in Oral Medicine. In most Dental Schools and some DGHs these clinicians are responsible for the investigation, management and follow up of patients with suspicious lesions and premalignancies, and are the first point of contact for most urgent referrals. They have an important role to play, and where appropriate are an important members of the MDT	The following phrase has been added under 'routine referrals', section 1: 'some are identified in oral medicine departments of dental hospitals'
British Society for Oral and Maxillofacial Pathology	P43	The report states that specialist pathologists should be part of the MDT. However specialist pathologists are not defined. The authors should be aware, that the only group of pathologists specifically trained in head and neck pathology are Oral and Maxillofacial Pathologists. Other H&N pathologists are general pathologists with a special interest. Currently there are about 25 consultant-level Oral Pathologists in the UK (all but 1.5 in Dental Schools). A total of only 45 pathologists in the UK participate in the Royal College of Pathologist approved Head and Neck External Quality Assurance Scheme. The requirement for	We do not define specialists except in terms of all MDT members who 'should specialise in head and neck cancers'. We do not believe it is feasible to define beyond that point. The reference to EQA schemes is generic to Pathology Depts and is in all the IOG Guidance documents. There may be merit in moving towards H&N specific EQA but this is not specifically recommended.

		participation in a relevant EQA scheme is stated on page 81 of the report. Technically therefore only 45 pathologists in the UK currently meet the criteria to be included in H&N MDTs.	
British Society for Oral and Maxillofacial Pathology	P59	Resources: It states that more CNSs are needed. This applies also to pathologists (see above) as well as other staff.	A generic statement has been added to the resource implications. The draft economic review is available at the second consultation.
British Society for Oral and Maxillofacial Pathology	P61	See point above. Reference here to a pathology EQA scheme, should state that the scheme should be relevant – in this case, the National H&N EQA managed by the BSOMP.	The document does refer to the general EQA scheme for pathology laboratories which is consistent with other guidance.
British Society for Oral and Maxillofacial Pathology	P94 and general	Resources: this section includes a long list of audit requirements. Few MDTs have support to do this and an audit clerk should be included in resource requirements.	Agreed. This is flagged up in the revised key recommendations.
British Association for Parenteral & Enteral Nutrition (BAPEN)			This organisation was approached but did not respond.
British Association for the Study of Community Dentistry (BASCD)			This organisation was approached but did not respond.
British Association of Art Therapists			This organisation was approached but did not respond.
British Association of Endocrine Surgeons	Page 9	The BAES is pleased to note that the guidelines acknowledge the radically different biology and clinical context of thyroid tumours in comparison with UAT tumours and applauds the separation of the document into sections dealing separately with the two tumour groups. The BAES was however disappointed that the document recycles some very archaic notions about thyroid surgeons and seems to fail to appreciate the extensive changes that the	See response to point below.

		specialty has undergone in the last ten years including the advent of specialty exams, national guidelines, and a composite national audit. Suggested text corrections to address this appear below. We were also disappointed that the role of the British Thyroid Association and its work is unrecognised here.	
British Association of Endocrine Surgeons	Page 22	Invasive cancer is found in significantly less than 10% of the population group described if Follicular lesions of the thyroid are correctly categorised into benign and malignant.	Please clarify the point and send supporting evidence.
British Association of Endocrine Surgeons	Page 25	Some papillary thyroid cancers are familial.	Too much detail.
British Association of Endocrine Surgeons	General	I write as President of the British Association of Endocrine Surgeons. We are very disturbed to see that the Nice draft guidelines on Head and Neck cancer include Thyroid Cancer and nodules as if they presented routinely to Head and Neck cancer clinics (which they do not), were a routine concern of head and neck cancer teams (which in general they are not) and can be managed in generically the same way (which is frequently inappropriate). We are also very disturbed that these guidelines have reached an advanced stage without any reference to the British Association of Endocrine Surgeons, or, as best I can judge from your list of registered stakeholders, the British Thyroid Association. 85% of Thyroid surgery in the UK is documented as being done by members of the BAES, and only a small percent by ENT, Head and Neck and Maxillofacial Surgeons . Endocrine surgeons have a specific curriculum leading to qualification in thyroid and endocrine surgery at the CCST level and also have a European Specialist Exam (UEMS). The BAES already has guidelines on the management of thyroid cancer and meshes these carefully with those of the British Thyroid Association. Our guidelines are currently being refined (see www.baes.info) . In this context I hope you will allow us the privilege of commenting on these guidelines and correcting some of the misconceptions about normal practice in the care of thyroid disease that have already reached the text.	There has been considerable re-drafting of the section on structure of services, including that relating to thyroid cancers, and the thyroid cancer MDT. Additional text includes the following: ***'Thyroid cancer MDTs*** All patients with thyroid cancer, including those whose cancer is discovered during surgery for apparently benign disease, should be referred for management by thyroid cancer MDTs. These teams may take one of two alternative forms, being either: 1. Designated head and neck cancer teams, joined by experts in endocrinology for the relevant part of the MDT meeting; or 2. Specialised endocrine oncology teams. Since thyroid cancer is a relatively rare condition, with an incidence rate of roughly two patients per 100,000 population per year, these MDTs will also only be required in large centres (those which serve populations in excess of a million). Thyroid cancer MDTs may manage patients with both malignant and non-malignant disease.'

British Association of Head and Neck Oncology Nurses (BAHNON)	Key recommendations	We agree that each MDT should include clinical nurse specialists, but not that they should "be involved in the care of every patient." This is not practical and above all not all patients wishes to see a CNS.	The text on the role of the CNS has been substantially revised.
British Association of Head and Neck Oncology Nurses (BAHNON)		Clinical Nurse Specialists- there does seem to be lack of agreement here: CNS may not be able to see 'every patient' on holiday/study leave, time management for project work .Other issues are • Patient choice specifically with earlier cancers, • de-skilling of other staff (if other staff see patients however, they need to have the skills to start with i.e. Communication (not just with patients but with other health professionals in all sectors), information giving, clinical). Should there be training for cover? *Patients do want information around the time of diagnosis. Not just this but help to understand the information being given. They pinpoint the CNS as the most appropriate person to be giving the information but this may be in part due to the way multidisciplinary teams function* • Every patient should have the contact numbers (i.e. CNS, Consultants secretary) right from diagnosis. Copies of letters or fax to GPs of all new diagnosis should go to CNS. Time before the treatment decision is made at the MDT can be essential for assessing the patient's psycho-social status, alcohol and smoking history and patients knowledge and understanding. Much can be achieved during this time and the CNS can also have input at the MDT about the patient's circumstances • Treatment decision- is often more complex now there is more choice for surgery Vs chemo-radiotherapy or laser versus radiotherapy- this is often an important role for the CNS as they are able to work in a flexible way (and across sectors) with a patients/carers particular needs in mind	The text on the role of the CNS has been substantially revised.
British Association of Head and Neck	Pg.8	P 8. Not necessary for CNS to be involved in care of every patient. Should be a referral system in place for referral to CNS. Every patient should have access to oncology qualified nurses	The text on the role of the CNS has been substantially revised.

Oncology Nurses (BAHNON)		and ENT/head and neck nurse practitioners who (as well as other health care professionals) can refer as appropriate. For example, does every patient having radiotherapy for a small localised laryngeal tumour really need Head and Neck CNS involvement? In addition there are not sufficient nurses and we are never ever likely to have enough at CNS level to see every H&N cancer patient throughout their cancer journey.	
British Association of Head and Neck Oncology Nurses (BAHNON)	Pg.8	P 8.Specialist services – the physiotherapist plays a vital role and perhaps should be included in this list.	The wording of the key recommendations has been substantially revised.
British Association of Head and Neck Oncology Nurses (BAHNON)	Pg.8	P 8.There remains a real issue of specialist services being involved with head and neck patients as this paragraph states not just for initial assessment but long-term. So specialist services should not just be available but resourced properly. There is no mention of physiotherapy here and it should be along-side the others (many patients have chronic chests and also give up work or some activity due to shoulder dysfunction)	The wording of the key recommendations has been substantially revised. The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation.
British Association of Head and Neck Oncology Nurses (BAHNON)	Pg.8	P 8. Data collection services should be more emphasis on what support means- if Specialist Services are going to undertake research will money and time be made available? Data collection should have equal emphasis on treatment and rehabilitation- as this information may influence patient's treatment decisions in the future. Survival Vs quality of life.	The wording of the key recommendations has been substantially revised. A recommendation is now also included about the importance and urgency of research into the effectiveness of management.
British Association of Head and Neck Oncology Nurses (BAHNON)	Backgro und	P23, 2nd para line 3, typo error – larynd instead of larynx	The wording of the key recommendations has been substantially revised.
British Association of Head and Neck Oncology Nurses	1.	Urgent referral (p28) • Pain: Sometimes the patient can present with referred earache (or odynophagia) unaware of a lesion in the oropharynx or persistent sore throat • Loss of sensation: can be implicated in parotid carcinoma	The urgent referral criteria are taken verbatim from the DH criteria. These are currently being revised by NICE.

(BAHNON)		• Stridor: is implicated in thyroid cancer (30) but should also be implicated in the urgent referral in cases of laryngeal or pharyngeal cancer (p28) • Persistent cough/irritation • Audiological symptoms- tinnitus/otalgia/deafness (earliest primary symptom of nasopharyngeal ca can be blood stained mucous or Eustachian tube blockage) • Neurological symptoms- instead of cranial neuropathies- (headache, cranial nerve palsies, diplopia) • Horners syndrome- can be a clinical feature of nasopharyngeal carcinoma • Unilateral nasal obstruction or discharge/epistaxis • Trismus • Bleeding or contact bleeding	
British Association of Head and Neck Oncology Nurses (BAHNON)	Page 30	A. Recommendations. A specific maximum time should be attached to 'promptly and appropriately', 'without delay' and 'regular contact' or they may be open to misinterpretation.	This should be determined at network level, depending on local circumstances.
British Association of Head and Neck Oncology Nurses (BAHNON)	2.	Members of the head and neck cancer MDT (p39): • The physiotherapist with a specialist interest in head and neck cancer- should be mentioned here. Their input is essential especially because many patients have underlying chronic chest problems (usually associated with smoking) and one of the continued rehabilitation problems is shoulder dysfunction (previous audit has shown it to be the most common symptom (before dry mouth) over two years after treatment). Patients are saying that they are getting conflicting advice. • Dental hygienist or nurses- essential for most if not all patients	Both of these are in the extended team, but would not need to attend each MDT.
British Association of Head and Neck Oncology Nurses (BAHNON)	P 40	Dietitian should have more than just a 'special interest' if they are to effectively meet the needs of this patient group. If MDT is dealing with at least 100 cancers a year this should be a full time post.	The bullet point now reads 'dedicated dietitian' and a paragraph describing the role of the dietitian has been added.
British	P48	Dental Services	We have covered the first point in our text; the second

Association of Head and Neck Oncology Nurses (BAHNON)		Needs to be clear that the Restorative Consultant should assess the patient before their operation and make arrangements to be available in theatre- for maxillectomy patients	point is not precluded, but brings a level of detail we feel is inappropriate in service guidance.
British Association of Head and Neck Oncology Nurses (BAHNON)	P48	Psychological Services There should be education and support made available from psychological services for staff caring for these patients. They are hands on and can often screen patients for depression and anxiety. But they can also be supported in dealing with difficult situations with patients- this is constructive in supporting staff but also they are on the front line and need to be enabled to learn psycho-social skills	This is a generic issue, covered in 'Improving supportive and palliative care for adults with cancer'.
British Association of Head and Neck Oncology Nurses (BAHNON)		The Clinical Nurse Specialist P41 The CNS should not take on the administrative burden of MDT meetings as this is not an appropriate use of their skill or time	Agreed. This point is made in the document.
British Association of Head and Neck Oncology Nurses (BAHNON)		CNS's can be instrumental and demonstrate strategies for bringing about closer collaboration and between team members not just within their department but across all boundaries of care. This is ultimately beneficial for patients and carers and education.	Agreed. No change required.
British Association of Head and Neck Oncology Nurses (BAHNON)		The role of the CNS in providing information and advice is advocated within this document. The nursing teams can access this advice and support. Nurses on the wards and with the outpatients are very knowledgeable and capable; these skills should be promoted and built upon. Many patients feel well supported by the nursing team and do not require the services of the CNS. The CNS should play a crucial role in the MDT. This will enable him/ her to have a background knowledge of the patients pathology and suggested treatment plan, enabling the CNS to discuss these issues and contribute to the decision making process. However, the CNS is not an isolated person, he/she	The section on the CNS has been re-written, to emphasise the CNS's pivotal role, without going into too much clinical detail.

		should be a team member within the nursing teams and other specialist agencies that help in the care delivery for the head and neck patient. It would be impossible for one CNS to cover all the elements as suggested in this document, particularly where cover is required on large sites and multiple hospitals. It would require a large team of CNS post holders.	
British Association of Head and Neck Oncology Nurses (BAHNON)		Patients should have access to the CNS rather than the CNS should be available to support every patient. It would be helpful to include a statement clarifying direct and indirect intervention by the CNS and that some patients' care can be managed by other members of the multidisciplinary team without direct intervention from the CNS.	The section on the CNS has been re-written, to emphasise the pivotal role, without going into too much clinical detail. The roles of other key disciplines have also been included.
British Association of Head and Neck Oncology Nurses (BAHNON)		Equally there may be some patients who do not wish to see the CNS initially though this may change throughout the pathway. Contact details should be provided as already stated.	The section on the CNS has been re-written, to emphasise the pivotal role, without going into too much clinical detail. The roles of other key disciplines have also been included.
British Association of Head and Neck Oncology Nurses (BAHNON)		Page 44 End of 3rd para. Not all CNS's have direct responsibility for managing patients with tracheostomies, gastrostomies, prostheses and difficult wounds. I suspect this will depend how the role evolved initially – however, the CNS should be able to sign post to the most appropriate professional.	See above.
British Association of Head and Neck Oncology Nurses (BAHNON)		I would believe the wording should be 'Access' and not 'Available'. There appears a lack of PCT involvement and collaboration. Diagnosis through to rehabilitation is multi-professional approach. This maybe co-ordinated through a CNS however a CNS does not necessarily follow up for a 'considerable time after discharge'. Appropriateness of referral and specialist need, working with primary carers needs to be considered. The CNS is a specialist resource, not a generalist resource!	Assume that this is covered by the response below; if not, please clarify.
British Association of Head and Neck Oncology Nurses		The document reads that the CNS '…should be available to support every patient, throughout the course of the disease.' This statement needs a further paragraph of contextualisation to clarify the service offered by the CNS. Each patient is an	Agreed. This is now covered by additional text relating to the Clinical Nurse Specialist.

(BAHNON)		individual and therefore needs individualised care. Current service provision means that there is a head and neck treatment centre into which referrals are made from satellite hospitals or head and neck units. Where there is no head and neck CNS provision at a satellite unit, and a diagnosis is made prior to referral into the centre, indirect interventions can be made through agreed protocols with the CNS at the cancer centre. Following referral to the CNS, direct interventions can take place, for example telephone follow-up by the CNS. This allows CNS guided intervention to occur, without the physical presence of the CNS, by experienced and skilled nurses in the satellite units. If, following consultation with my colleagues, the editorial board feel that there is no need for this contextualisation, then there should be explicit reference made to the resources needed to provide this element of care.	
British Association of Head and Neck Oncology Nurses (BAHNON)		"A H&N CNS should be available to support every patient, throughout the course of the disease" would it be more patient focused to say for those who require or request it?	'Available' implies 'if required'.
British Association of Head and Neck Oncology Nurses (BAHNON)		I am puzzled as to why there so much on CNS role in comparison to others, for example AHPs. If CNS sees every patient throughout there is going to be a need for an enormous increase in numbers of CNSs. Even then the CNS is likely to be very thinly spread across all patients and carers with the potential for s/he to be providing care and information that can be effectively delivered by a less experienced nurse. Is this the best use of such an experienced person? Would it not be better for a referral system to be in place so that those with specific specialist needs can benefit from in depth input from this specialist nurse.	The balance has now been changed in the text, with additional information on other roles now included.
British Association of Head and Neck		P51-concerns on centralisation increasing waiting times for treatment; should some comment be made regarding recognising the issues for often elderly patients and carers of increased	This paragraph reports the findings of the SWAHN II audit. It is not a recommendation.

Oncology Nurses (BAHNON)		travelling and subsequent anxiety, fatigue and expense particularly within rural areas.	
British Association of Head and Neck Oncology Nurses (BAHNON)		P55-"Evidence that every patient is interviewed by a CNS and given her contact telephone number" would it be more appropriate to state every patient will be given contact telephone number for CNS on diagnosis, this may be delivered by appropriately trained outpatient staff who will have access to information literature and direct contact with CNS in any difficult circumstances-resource implications for any large trust, need to consider patient:CNS ratios.	At some stage, every patient should be seen by the CNS. No amendment.
British Association of Head and Neck Oncology Nurses (BAHNON)		I firmly believe it is not necessary for every patient with head and neck oncology disease to be seen by a CNS. This will depend upon the treatment each patient receives, the level of patient need such as the stage of care required by each patient. The CNS would, I agree, be an essential member of the care team, working in partnership with the team as advisor/supporter in planning the patient's care journey and treatment. The CNS role would work with the generic nursing team as a partner in the delivery of care. The majority of nursing care would be provided by the generic nursing team. However, every patient should have access to a CNS as and when required.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that all patients are assessed by a CNS.
British Association of Head and Neck Oncology Nurses (BAHNON)	P 55	Process, Point 3 – "Evidence that every patient is interviewed by a CNS & given her contact number". This will be difficult to evidence as not all patients need or wish to be interviewed by the CNS. It would be better to say offered access to the CNS and given their contact	At some stage, every patient should be seen by the CNS. No amendment.
British Association of Head and Neck Oncology Nurses (BAHNON)	P55	Again I believe all patients should have access to a CNS and be given a contact number however I do not believe every patient should be 'interviewed' by a CNS	See above.
British Association of Head and Neck	P 58	I do not feel it is essential for all patients to be seen at the time of diagnosis by the CNS. This devalues other nurses who are highly skilled in dealing with these situations.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that

Oncology Nurses (BAHNON)		Contact numbers can be given with information as to the role of the CNS and an explanation that they can be contacted at any stage of their cancer journey. It is more appropriate that the CNS be available for patients with complex needs, for whom more time, information and support may need to be provided/organised.	all patients are assessed by a CNS.
British Association of Head and Neck Oncology Nurses (BAHNON)	P58	Informing Patients "The diagnosis and its implications should be discussed with the patient by a senior member of a Head and Neck Cancer MDT, in a quiet, private room with no distractions. Each patient should be supported during and after this consultation by a Clinical Nurse Specialist (CNS)." Once again this assumes that the CNS should see every single individual patient. This is unworkable without large numbers of CNS's on each team, particularly when working across different hospital sites/trusts. Within the different sites there are nursing teams with highly skilled nurses who would be both deskilled & devalued if the CNS was to be present during every consultation where the diagnosis and implications are discussed. Where there are concerns identified that the nurse in clinic could not address then they would refer on to the CNS.	This text has been revised to be consistent with the revisions to the CNS role. This text now reads as follows: 'Each patient should be supported both during and after this consultation by a suitably trained nurse. The Clinical Nurse Specialist (CNS) should be informed about each new patient when a definitive diagnosis is made and may provide direct emotional support at this time; alternatively, she (or he[1]) may delegate provision of such support to another named nurse.'
British Association of Head and Neck Oncology Nurses (BAHNON)		Informing patients. Is CNS really needed for every patient? What is meant by a senior member? Should be a consultant Head and Neck Surgeon and/or consultant Medical Oncologist. The comment on communication skills training for all is excellent	See response to point below.
British Association of Head and Neck Oncology Nurses (BAHNON)	P58	The document reads at diagnosis 'Each patient should be supported during and after the consultation by a CNS'. I do not believe that this is true. Each patient does need support through this difficult period but it does not always have to be by a CNS: for simple cases it could easily be provided by an experienced clinic nurse who has the appropriate skills. Nursing care is individualised for each patient. It is entirely	The text on the role of the CNS has been substantially revised and re-drafted.

[1] In the text below, the pronoun "she" may be used for convenience to refer to the CNS or other nurse; it is acknowledged that the nurse may be male.

		appropriate, therefore, that not every patient with head and neck cancer (and pre-malignant conditions) will need the specialised care provision at diagnosis of a head and neck CNS (just as not all palliative patients do not require access to specialised palliative care services): care should be tailored to each individual. If the less specialised elements of care can be met by, for example, by an experienced clinic nurse at diagnosis, then this should occur. Of course, this does not exclude patients from accessing the CNS service at a later date. If we, as CNS's, take over this role completely, then we begin to deskill these nurses in clinical practice. This raises strategic questions about succession planning and provision of future and present services. Already, there is difficulty recruiting suitably qualified personnel into the CNS role – by implying that the CNS should undertake all these roles will possibly lead to compounding this problem.	
British Association of Head and Neck Oncology Nurses (BAHNON)		Many centres currently employ one whole time equivalent providing the CNS role. If other nurses caring for head and neck patients have not had the opportunity to develop these skills by providing this care, who provides care during periods of CNS annual leave and study leave? Organisational, cultural and geographical barriers currently exist in many centres to prevent a CNS being present at all diagnosis consultations. However, simple resource implications should first be addressed (ie appropriate support in terms of administrative support and access to equipment) with existing CNS posts to allow them to undertake their role more effectively at the moment. If following these comments, the editorial board felt that a CNS should be at all diagnosis consultation, it should be noted that the resource implication would be massive in the creation of many more CNS posts, both in specialised centres where a CNS exists and in the smaller units that refer into the specialised centre. A strong strategic plan would also be needed to address the issue of deskilling and succession planning.	See response above.

British Association of Head and Neck Oncology Nurses (BAHNON)		A general nurse may be the most appropriate professional to inform patients of their diagnosis with the lead clinician. It is not essential that a CNS is present when informing patients of their diagnosis, I do see the CNS as a core member of the MDT and agreeing in partnership with other professionals, the plan of care. There appears to be a lot of unrealistic expectations within the document with regard to the CNS role and time and a lack of acknowledgement with regard to the general nursing team.	See response above..
British Association of Head and Neck Oncology Nurses (BAHNON)	P58	As above, it is not always necessary or possible for the CNS to see every newly diagnosed patient. CNS is often expected to attend more than 1 clinic at the same time and needs to prioritise workload and assess patients need for support unseen! E.g. An elderly gentleman with SCC pinna may need less support that a 40 year old man with a large tonsil tumour and a family to support. This is made possible by close liaison with ward and clinic staff and through training and educational support from the CNS-in this way nurses are kept up to date and not de-skilled by the interventions of the CNS.	See response above.
British Association of Head and Neck Oncology Nurses (BAHNON)	P58	It is never possible to guarantee that a CNS can be there to support each patient before and after the consultation and needs to read something along the lines of 'either the CNS or other designated health professional', so that in areas that do have out-patient staff experienced enough to deal with patients and their families that they should continue to utilise those skills.	See response above.
British Association of Head and Neck Oncology Nurses (BAHNON)	P59	Where it talks about being introduced to others who have been through similar treatment etc it says that they should have been trained by a CNS, SALT, or Psychologist. I would not feel able to train an 'ex-patient' to talk to a prospective patient. What about 'CancerVoices' training that Macmillan Cancer Relief provide?	Agreed – eg has been inserted in the brackets and the suggested reference added.
British Association of Head and Neck Oncology Nurses (BAHNON)	P59	"There should be a defined mechanism … to ensure that patients….are introduced to others…and who have been trained in supporting newly diagnosed patients" this requires clarity- what specific training is available? Also "trained ex-patients" mentioned on P63 Unclear if this is to be recommended for all H&N patients or just laryngectomees	See response above.
British		Should there be comment made re use of panendoscopy in initial	This suggestion seeks more detail than this guidance

Association of Head and Neck Oncology Nurses (BAHNON)		investigation and diagnosis section 3 P57- evidence of second primaries for any H&N cancer	aims to provide about the clinical protocols for investigation, particularly in the light of the variety of tumour sites involved.
British Association of Head and Neck Oncology Nurses (BAHNON)	4.	Should include Physiotherapy- shoulder function pre-op and chest	The comment about physiotherapy is felt to be at too great a level of clinical detail for service guidance. The physiotherapist is identified as a member of the Extended Team.
British Association of Head and Neck Oncology Nurses (BAHNON)		Dental assessment should include restorative dentist for patients considering maxillectomy	The section on dental assessment will have a reference to restorative dentistry added as follows: There are two short paragraphs on Dental Assessment on page 70. The following sentence has been added to the first paragraph: 'Patients who are to undergo radical therapy should have access to specialist dental services provided by a restorative dentist.'
British Association of Head and Neck Oncology Nurses (BAHNON)		Psycho-social assessment is imperative- CNS can be instrumental in informing the community team (sometimes an 'outreach' visit) is very constructive and any social needs can be addressed and considered which will often reduce delays in discharge or smoother functioning/communication across sectors. Increasing satisfaction and trust from patients.	The importance of psycho-social assessment is already highlighted.
British Association of Head and Neck Oncology Nurses (BAHNON)		Difficult symptom control useful to refer to Palliative Care Consultant for advice	Palliative services are integral to the MDT and specified as core membership.
British Association of Head and Neck Oncology Nurses (BAHNON)		Advice from benefits advisors and social services can be invaluable specifically at this time for patients who have financial difficulty, are self employed or have social problems or are limited in any way and need carer support in the home	Again these issues have been flagged up in the membership of the MDT and in particular the Extended Team members. These include social work and benefits advice.

British Association of Head and Neck Oncology Nurses (BAHNON)		Dietitian to be included as well as CNS and SALT in view of effects radical treatment has on eating and drinking.	It is simply not clear to what this comment refers.
British Association of Head and Neck Oncology Nurses (BAHNON)		Occupational Therapy- for patients requiring equipment or assessment of need. Bearing in mind this group many are elderly.	The Measurement section will be revisited. This particular point may not be appropriately dealt with in this context; however, along with one or two other comments it does raise the role of occupational therapists in the provision of patient support aids and appliances in the community. Will consider whether some addition needs to be made. Please note that generic issues such as the role of OTs are covered within the recently published NICE Guidance on Supportive and Palliative Care.
British Association of Head and Neck Oncology Nurses (BAHNON)		Resource implications: Agreed sessions for Dietitian, physiotherapy, dental hygiene and psycho-oncology time.	Resource implications for a range of disciplines in providing support and rehabilitation are being examined in the Economic Review.
British Association of Head and Neck Oncology Nurses (BAHNON)	P65	Measurement of QOL should be given more priority in the document (is mentioned on P103)- if this data were gathered routinely national audit could be achieved (BAHNO recommends University of Washington questionnaire). Also are HADS or other tools to measure psychological state to be recommended?	References to DAHNO are now included. It includes the ECOG measure of performance status, to be recorded after one year (now mentioned). There is no evidence on which to base a recommendation about a particular tool.
British Association of Head and Neck Oncology Nurses (BAHNON)		Once treatment decision is made and is going to have an affect on swallowing (whether surgery and/or radiotherapy). Consultant, Dietitian, CNS and SALT to discuss type of enteral feeding (if patients are likely to need enteral feeding for more than a month-6 weeks, a PEG/RIG should be considered and weighed up with possible complications). Primary Health Care Team should be made aware of these decision so preparation can be made at home and education given to patients and relatives (this is often a source which delays discharge and adds to morbidity of patient).	This section has now been re-drafted and expanded to take account of these comments. It now reads as follows: **'Preparation for treatment effects on speech, nutrition and swallowing** Both surgery and radiotherapy can cause difficulties with speech, eating and swallowing. There should be written

			protocols and guidelines, agreed by all head and neck cancer MDTs in the Network, for the nutritional management of patients who are to undergo these types of treatment. There should be specific guidelines on the use, placement and management of gastrostomy (PEG) tubes. When it has been decided that a patient is to have treatment that will affect eating or swallowing, the surgeon and/or oncologist, dietitian, CNS and SLT should discuss the method of feeding that will be used. The Primary Care Team should be informed well in advance about patients who may be tube-fed for more than a month, so that preparations can be made for the patient to be supported at home. A member of the MDT should explain these issues to the patient, to ensure that he or she is prepared for any interventions that may be required before treatment begins. Patients and carers should be given specific advice on food preparation and diet to maintain adequate nutrition during outpatient treatment and after discharge from hospital. Patients whose treatment is likely to affect their ability to communicate should meet their speech and language therapist (SLT) before such treatment begins. The SLT should explain rehabilitation strategies with the patient and carer, describing how she will work with them to maximize the patient's potential for recovery of speech, voice and swallowing.'
British Association of Head and Neck Oncology Nurses (BAHNON)	5.	Conflicting statements on centralisation issues P76 states "patients who require radical surgery should be managed by the MDT in a cancer centre. P5 states "ideally, diagnosis, management and subsequent support should be provided locally".	There is no conflict here. The reference to page 5 in the Foreword is simply a description of the dilemma facing the guidance developers and the quote is taken out of that context. Similarly the recommendation for centralisation is counter-balanced by some degrees of delegation at the discretion of the MDT. This comment is not accepted.
British	P81	States "there is consistent evidence that minimising treatment	Anaesthetic assessment. The sentence now reads:

Association of Head and Neck Oncology Nurses (BAHNON)		time can be crucial to the success of radiotherapy for head and neck cancers" yet clearly by centralising services time to treatment is lengthened sometimes significantly, particularly as there is no reassurance that resources will be attached to any centralisation policy.	'Patients who are to undergo surgery which will involve the airways should be assessed by an anaesthetist who works regularly with surgeons on the MDT'.
British Association of Head and Neck Oncology Nurses (BAHNON)	P77 & 84	Serious concerns about the recommendations on use of topical treatments for patients with mucositis associated with radiotherapy (antibiotic lozenges, ice chips, hydrolytic enzymes, GMCSF). These products are currently unlicensed for such use in the UK. How much will they cost? Especially GMCSF which costs around £100 per patient per day! And is there really enough evidence to recommend them in this document? Were some of these studies specific to head & neck cancer, which obviously has very special considerations for mucositis interventions. For example, ice chips are only useful with bolus chemotherapy (it causes local vasoconstriction, therefore lowering the amount of cytotoxic delivered to the oral mucosa.) This would clearly be highly detrimental if the tumour being treated was in the oral mucosa!!!. Patients having chemotherapy over several days (most head & neck regimes are over 5 days) would need to keep a mouth full of ice chips for 5 days to have any effect. I think that the ice chips studies are not pertinent to head & neck cancer. Why is this under the heading 'Radiotherapy' in any case?	This is covered in the revisions to this section. This revision is accepted.
British Association of Head and Neck Oncology Nurses (BAHNON)		There are many other studies on oral mucositis management e.g. Gelclair R (Innocenti M *2001 Efficacy of gelclair in reducing pain in patients with oral lesions-preliminary findings from an open pilot study*. Unpublished) which forms a protective adhesive barrier over the surface of the epithelium. Why have these not been included in the review?	This is an inappropriate level of detail; we have decided on a strategy of reducing the clinical detail about precise therapies for mucositis in favour of a more general requirement to address and manage the issue satisfactorily in the interests of patient welfare and the completion of treatment.
British Association of Head and Neck Oncology Nurses (BAHNON)	7.	Importance of referral to palliative care with patient's consent and knowledge of reason should be stressed. Referral should be made as early as possible so that patient and carers can gain maximum benefits from the range of services and support, including rehabilitation, listed at start of this section. The refusal of some consultant surgeons to refer their patients for palliative care as they think they are better at it mainly because they have known patient and family for longer is still happening. One does	Agreed. The palliative care specialist is a core member of the MDT. The text has been augmented to emphasise this point.

		not deny their knowledge of the patient and family and the excellent relationships that may have been built up over time. However they are not palliative care consultants or specialists and recognition of the unique contribution that specialist palliative care can make to patients and families needs to be stressed.	
British Association of Head and Neck Oncology Nurses (BAHNON)		I have some concerns regarding all acute airway obstruction patients going straight to a ward area eg on a Saturday evening especially if just after changes in staff who are on rotation programmes such as SHO. It may be easier and safer to treat or do an emergency tracheostomy in an accident and emergency department. Present day communication systems and skills of paramedics should ensure they are able to communicate status and needs of patient en route so that appropriate specialist staff are available in A&E when patient arrives.	The intention is for appropriate patients to be able to go straight to the ward. Patients in the example quoted would go to A&E. The wording has been revised from 'patients with acute airway obstruction are admitted' to patients with anticipated acute airway obstruction can be admitted'.
British Association of Head and Neck Oncology Nurses (BAHNON)	P95	Management of airway obstruction. This specific issue related to the management of patients with laryngectomy stomas (end tracheostomies) is very important and not just in palliative care. Patients who are disease free have the same issues with lack of knowledge amongst health care professionals. This needs addressing somehow earlier in the document.	This is covered in the re-vamped section on aftercare, rehabilitation and support.
British Association of Head and Neck Oncology Nurses (BAHNON)	P96	States "choking or bleeding to death is particularly feared" practical support is available through BAHNON guidelines on carotid blowout (download from www.bahnon.org.uk). Also tracheostomy guidelines are available to guide the management of airway obstruction. Does comment need to be made within guidance about this?	Should be covered in local protocols.
British Association of Head and Neck Oncology Nurses (BAHNON)	8.	This is an excellent section and the concept of local support teams will only benefit the patient and carers through meeting the long-term needs.	No response required.
British Association of Head and Neck Oncology Nurses		Difficulties experienced by patients - include fatigue as it is a significant problem for many.	Reference to this has been added.

(BAHNON)			
British Association of Head and Neck Oncology Nurses (BAHNON)		Delighted to see inclusion of nurse practitioner, who could and should be involved much earlier and so work with CNS. ? SALT should be doing valve management rather than a nurse.	No amendment proposed. .
British Association of Head and Neck Oncology Nurses (BAHNON)	P102	Could nurse led review be considered/acknowledged for patients after first 2 years of follow up "when 90% of recurrences develop"?	This possibility is not excluded.
British Association of Head and Neck Oncology Nurses (BAHNON)	P103/105	Pilocarpine has many side effects and in our experience rarely tolerated; could the editorial board consider mentioning the use of acupuncture for pilocarpine resistant xerostomia; acupuncture has some evidence that it can stimulate saliva to varying degrees (Niemtzow et al N5EV@msn.COM)	The text has now been re-worded.
British Association of Head and Neck Oncology Nurses (BAHNON)		It can be difficult to screen for problems in the long-term as Consultants have a long list of patients to see and the CNS is running between often many clinics running at the same time. We need to look at structure of follow-up clinics or have a screening tool (i.e. Quality of life) so problems are recognised and followed up as necessary	Already covered in the text.
British Association of Head and Neck Oncology Nurses (BAHNON)		The CNS should be able to discharge patients the same as any other health care professional. Contact details should be for Head and Neck clinical area and services. There is no reason to expect the same CNS to be in post. If decided that CNS is to be contact then it should read the or an CNS rather than their CNS.	Agreed. The text has been amended.
British Association of Head and Neck Oncology Nurses (BAHNON)		There is no mention of shoulder dysfunction- where patients often require ongoing physiotherapy. Patients coming back after radical surgery and radiotherapy often have poor mobility of their shoulder and there should be an agreed strategy for dealing with this	Reference has now been made to this need.

British Association of Head and Neck Oncology Nurses (BAHNON)		I think there are several assumptions made about nurses eg reducing staff turnover and making the jobs more interesting – good idea but what evidence is there for these statements? There is a dearth of suitable applicants for CNS posts in all specialities for a variety of reasons eg a national shortage of registered nurses. Any strategies for improving retention are to be encouraged.	No response required.
British Association of Head and Neck Oncology Nurses (BAHNON)		There is not enough emphasis on the vital importance of restorative dentistry in this section. Many patients have had all of their teeth removed and understandably are desperate for a set of dentures. Unfortunately due to lack of resources, they often have to wait for months or even years. This affects their eating abilities even more, their speech, and very importantly, their feelings about their appearance. Don't need an RCT to evidence this!	Some text has been added on access to dental services.
British Association of Head and Neck Oncology Nurses (BAHNON)	General	There is little mention of the PHCT- ongoing liaison with them can make a difference to patient outcome and choices about their care. I.e. GP. Macmillan Nurse, Community Nurses. Benefits advice or social services information should be made available to patients- cancer and its treatment can often load a huge financial burden on the patient. This should be recognised before and after treatment.	The wording has been amended as follows at the beginning of Section 4: 'A CNS should be involved in this assessment, both to provide support and information, to become familiar with the patient's attitudes and domestic situation, and liaise with primary care teams and other agencies as necessary.'
British Association of Head and Neck Oncology Nurses (BAHNON)		Complications There is no section on complications- favourable and unfavourable outcomes- patients who experience complications can be immediately post-op but also long-term complications and for these they can be waiting for months for surgery as they are no longer considered a priority. Could there be consensus of opinion in these situations? Complications requiring in-patient stay should equally be discussed at MDT	Agreed. Reference has now been added to complications (section 8).
British Association of Head and Neck Oncology Nurses (BAHNON)		It would be useful if a record of place of death could be kept as this could be used for planning future services and education and training purposes.	Place of death is included as a data item in the Cancer Minimum Data Set.

British Association of Head and Neck Oncologists			This organisation was approached but did not respond.
British Association of Oral and Maxillofacial Surgeons	General	This document requires a major editorial review and a statement at the beginning explaining for whom it is directed. In places poorly written and many typos etc	See para1 of the Background section for the target audience. The final draft of the document is proof-read in detail.
British Association of Oral and Maxillofacial Surgeons	General	The British Association of Oral and Maxillofacial Surgeons (BAOMS) welcomes the opportunity to comment on the above document and broadly supports its philosophy and recommendations. BAOMS accepts that this is principally a document to inform the process of commissioning head and neck cancer services and not a clinical guidance document.	No response required.
British Association of Oral and Maxillofacial Surgeons		BAOMS agrees that all patients with head and neck cancer should: 1. Be managed *via* a multidisciplinary team (MDT) and agrees with the guidance recommendations for MDT membership and responsibilities. a. We would also suggest that: i. A surgical specialist with expertise in microvascular techniques (page 44) should be a core not an extended team member due to the importance of providing appropriate and high quality surgical reconstruction to patients that would benefit from it. ii. An anaesthetist with a special interest in the management of head and neck cancer patients should be included in the extended team. iii. While clinical nurse specialists (CNS) should be available to support every patient (page 46) it is unlikely that they will be able to personally be involved with the care of every patient (page 7) 2. Have comprehensive data collected throughout their cancer journey in order to monitor the quality of service and treatment	Topic 2, Structure of services, including the roles and membership of the MDTs, has been substantially revised. The text on the role of the CNS has been substantially revised and re-drafted.

		outcomes (page 92) a. We suggest that specific reference should be made to the national DAHNO project, which is aiming to collect such data on patient with oral and laryngeal cancer. b. We suggest a higher profile should be given to assessing quality of life after treatment for head and neck cancer BAOMS is very pleased to participate in this consultation, and we hope that these comments will be useful when you are formulating the final document.	Reference is now made to the DAHNO audit. Included in the DAHNO dataset
British Association of Otolaryngologists, Head & Neck Surgeons		"The process is very doctor and nursey orientated"	The developers do not agree with this view. Please supply specific reference.
British Association of Otolaryngologists, Head & Neck Surgeons		"The role for chemotherapy need to be strengthened"	The role of chemotherapy needs to be better researched; there is currently little reliable evidence of benefit.
British Association of Otolaryngologists, Head & Neck Surgeons		Generally an extremely good representation of head and neck cancer. We would, obviously, dispute the involvement of 'endocrine' surgeons, whatever they may be and certainly general surgeons, unless they be assisting in obtaining jejunal grafts for pharyngeal reconstruction. Audits have shown that general surgeons are 'low volume' operators in the UK. The best results from thyroid surgery for cancer will come from head and neck surgeons who include such cases in a multidisciplinary framework.	Endocrine surgeons are only mentioned in the Foreword, in the context of a discussion about what currently happens. The remaining comments are consistent with the recommendations in the manual.
British Association of Otolaryngologists, Head & Neck Surgeons		Patients and carers' main concern is survival: just ask them. Distances travelled in the UK are tiny compared to the treks undertaken to receive care in Australia, the United States and most of the less well-developed countries. Geographical difficulties should be an argument for excellent peripheral diagnostics and palliative care, but treatment should be entirely within centres.	Agreed. This comment is consistent with the thrust of the document.

British Association of Otolaryngologists, Head & Neck Surgeons		With respect to volume-quality, please also note Max Bachmann's paper (Univeristy of East Anglia) which shows a U-shaped relationship between cost and volume. Cost goes up initially, due to increased use of technology, whilst it subsequently goes down as capital costs lessen. These figures do not account for the enormous release in resource at the referring hospitals, where bed-stays can diminish from an average of 6 (for those 'doing' head and neck work) days to about 24 hours (data from Wessex). This would solve much of the country's problems with waiting lists in ear, nose and throat and, to a lesser extent, maxillofacial surgery.	Resource issues are covered in the economic review, available at the second consultation. Please forward any specific references.
British Association of Otolaryngologists, Head & Neck Surgeons		It is inconceivable that all the trusts presently doing low volume (say, less than 100 cases per year) work will be prepared to invest in all the extra doctors, nurses, rehabilitation staff, diagnostic and treatment capital and revenue that the present Guidelines implies, whereas the high volume centres already have most or all of these things in place. That is not to say that centralisation will not be without cost (e.g. unplanned centralisation on the South Coast led to devastating effects on ENT waiting times and on waiting times for cancer treatment), but the overall benefits in terms of improved care and survival, and the freeing up of other hospitals to get on with serving the routine needs of their local population instead makes the argument more than compelling.	No response required.
British Association of Otolaryngologists, Head & Neck Surgeons		"What and who are Core Members – This needs defining as well as what are the minimum staffing levels – two of each!	There has been considerable re-drafting of the section on MDTs, including specification of the core team.
British Association of Otolaryngologists, Head & Neck Surgeons		"What do the references to (A) and (B) refer to – please explain someplace preferably at the beginning"	The grading taxonomy will be explained in an Appendix, and referenced at the beginning of each 'Evidence' section in the final version.
British Association of Otolaryngologis		"The use of evidence is considered very poor and the seeking for supporting references must have been made very difficult and not done by doctors! – better to say that no evidence than poor	Systematic evidence reviews were undertaken to identify effective interventions, based on evidence. In many cases, that evidence was poor. That is different from

ts, Head & Neck Surgeons		evidence! There is enough support in the local UK literature to support what is done rather than seeking other national's evidence from esoteric literature!	there being no evidence (often also the case). For full details of the review, please see Research Evidence document accompanying the second consultation.
British Association of Otolaryngologists, Head & Neck Surgeons		Agreed that there is a need for dental hygienists and more importantly psychologists – where are we to get them from! and should they be available in every H&N MDT?	All H&N MDTs should have access to them; they are not core members.
British Association of Otolaryngologists, Head & Neck Surgeons		The impression that Speech and Language Therapy (SLT) is helpful should be strengthened and become less woolly! The College of SLT has produced a document of its own which should be referenced at the least if not included!	This is general background information; detail is given in relevant parts of the main document. The following text has however been added at this point to amplify the specific role of SLTs: 'who provide expert assistance with swallowing, communication and breathing problems'.
British Association of Otolaryngologists, Head & Neck Surgeons		Is there going to be a production of network wide or even national wide protocols?	It is expected that network-wide protocols will be produced as part of the means to implement the guidance (as referenced on P60 of the draft).
British Association of Otolaryngologists, Head & Neck Surgeons		What about MDT support – secretarial, data collection etc – please be explicit and needs to be in place FIRST rather than an ADD ON!	This is explicitly included in the core team.
British Association of Otolaryngologists, Head & Neck Surgeons		There is no reference in the document to super specialist MDT's – for skull base and salivary tumours	This is included in the first paragraph of page 42 of the draft.
British Association of Otolaryngologists, Head & Neck Surgeons		FNAC/Cytopathologists – are to be condoned, but where are we to get the expertise on a National basis!	This is a workforce issue beyond the brief of the guidance, although the fact that this will take time is acknowledged.
British Association of		Specific comment on the SWAHN Trial – suggests that the accuracy of the audit data was a lot to be desired and rather than	The SWAHN *audit* is used to highlight current services. NB: this is not a trial.

Otolaryngologists, Head & Neck Surgeons		giving the report weighting, its recommendations are best a guide! Certainly not a level 1 project!	
British Association of Otolaryngologists, Head & Neck Surgeons		Comment should be made of related cancers --- Lymphomas, paediatric H&N, Oesophageal, etc and their rehabilitation!	This guidance relates only to head and neck cancers in adults. Where recommendations impinge on services for other cancers, these implications are identified.
British Association of Otolaryngologists, Head & Neck Surgeons		What about skin tumours that invade bone and present with metastases – Is it recommended that there should be a relationship with head and neck cancer surgeons if not treated by H&N surgeons!	Such tumours are outside the scope of this Guidance. They will be part of the next tranche of work from the NICE Centre in Cardiff.
British Association of Otolaryngologists, Head & Neck Surgeons		Health promotion - cessation of smoking and alcohol needs greater emphasis?	There was a research question looking at alcohol and smoking cessation programmes on outcomes. No evidence was found on the alcohol question, and limited evidence for smoking cessation. There is reference to smoking and alcohol in the background section, the text for which has now been revised.
British Association of Otolaryngologists, Head & Neck Surgeons		Where is paediatric head and neck cancer in this document? This should be included in any service recommendations?	Paediatric cancers will be covered in a separate document (Cancers affecting children and young people), separately commissioned by NICE.
British Association of Otolaryngologists, Head & Neck Surgeons		As there is not defined budget for head and neck cancer within Trusts how is this going to be overcome?	The Page reference for this comment is needed for the developer to respond – see NICE guidelines to stakeholders.
British Association of Otolaryngologists, Head & Neck Surgeons		Patients continue to be admitted and cared for under a named clinician – how can we move away from the “blame culture” to a “service analysis of case mix and MDT sense of cooperation and decision making?	The whole concept of MDT management should guard against this.
British Association of Otolaryngologis		“More on resourcing, would have been welcomed as Head and Neck Cancer has never been resourced in the UK NHS”	The economic review will be available with the second draft.

ts, Head & Neck Surgeons			
British Association of Otolaryngologists, Head & Neck Surgeons		In summary; this document seems to be predicated on the completely unrealistic and unproven assumption that if only every patient were seen by an MDT everything would be fine. This needs to be challenged.	Personal opinion; developers disagree.
British Association of Otolaryngologists, Head & Neck Surgeons		Generally the section on rehab needs to be more clearly thought through .This doesn't currently explain the level of ongoing input these patients need.	The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatmentTopic 6 becomes 'Aftercare, rehabilitation and support'. There has also been some re-drafting of the material.
British Association of Otolaryngologists, Head & Neck Surgeons		Research: that all NCRI registered head and neck cancer trials should have ethical permission granted at every centre/network. In practice there is only one at present, but a handful more are expected in the next two years and a rapid answer will best be given by 100% participation by networks. I regard this as an ethical duty of head and neck teams.	Agreed; the following key recommendation has now been re-drafted: 'Research into the effectiveness of management – including assessment, treatment, delivery of services and rehabilitation – urgently requires development and expansion. Multi-centre clinical trials should be encouraged and supported.'
British Association of Otolaryngologists, Head & Neck Surgeons	Page 10.	The diagnostic and surgical skills required to deal with thyroid cancer are the same as those for neck surgery for squamous cancer. They are not 'totally unlike UAT cancers'. This is the sort of nonsense that 'endocrine' surgeons (who most commonly operate on that well-known endocrine organ, the breast) come out with.	The phrase 'totally unlike' has now been changed to 'dissimilar'.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 12	Excellent comments on the problems of classifying head and neck cancers for descriptive purposes. The NCRI annual reports have not come to terms with this yet!	No response required.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 16	Statistics and references from abroad 'unreliable'. This suggests that much of the criticism of the UK provision is based on an incorrect assumption that our service is in some way 'substandard'.	These are the only comparable available international data.
British Association of	Page 20	The larynx, para 2. '..most frequently affected in the UK' . Supraglottis is commoner in other parts of the world.	This is UK guidance. No amendment proposed.

Otolaryngologists, Head & Neck Surgeons			
British Association of Otolaryngologists, Head & Neck Surgeons	Page 21	Even squamous cancer of the nasopharynx has a different aetiology, unrelated to smoking. Undifferentiated NPC is commonest. It is a disease of the elderly in the UK, but of the young in North Africa and South East Asia, where it is related to Epstein Barr virus infection.	The text has now been revised.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 24	There is increasing interest in the increasing group of patients with HNC who have not been drinkers or smokers. Risk factors of particular note in these are HPV (Relative risk varies with site from 18 in the tonsil to 3 in the larynx) and laryngopharyngeal reflux (LPR). However, high quality case-control studies are lacking for these at present.	Too much detail for the Background section. Reference to HPV is already made.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 25	Young patients and risk factors: there is a good new study, published in Oral Oncology, 2004 which supports the premise that risk factors are important in young patients. In view of the clinical importance of this group, it may be worth including this reference.	The issue of risk factors is already addressed.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 26	Add extra sentence? "Biopsy is often done under a general anaesthetic which also allows better clinical staging of the tumour and exclusion of synchronous UAT malignancies."	Too much detail for the Background section.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 28	Last paragraph – with the introduction of National Lead Clinicians this lack of MDT demographics of what makes up a HnN MDT can be completed by the results of a questionnaire that should be available after 29th April 2004.	Please send results as soon as possible.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 30	"There should be a specific referral route for patients with neck lumps and thyroid nodules" – This is an ideal, and waits for evidence that more cancers will be identified! We need to perform clinical examinations and then tests rather than tests and then examinations! We still need more cytopathologists in HnN Clinics See page 39 recommendation 4!	This is an important recommendation relating to the way in which the service must work, to ensure that all patients are appropriately diagnosed and treated.
British Association of	Page 31	"see personally" – One assumes a consultant led clinic! We need more full time head and neck surgeons, to treat diagnosed	This is not about the worried well, but patients with suspicious lesions.

Otolaryngologists, Head & Neck Surgeons		cancers rather than more to screen the worried well?	
British Association of Otolaryngologists, Head & Neck Surgeons	Page 31	Urgent Referral Guidelines (England) are being revised --- can these not be included at this stage!	No, because they are not due out for another year (2005).
British Association of Otolaryngologists, Head & Neck Surgeons	Page 31	The comment that local units may not require a full MDT would be improved by a requirement to have formal links to a central MDT. The risk in the current statement is that local teams may operate outside a framework for quality control, especially if this part of the report is read in isolation.	This has now been clarified, with the addition of: 'but designated clinicians should have formal links with the MDT(s) to which they refer patients'.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 32	Neck lumps para 1. The success of these clinics depends crucially on the expertise of the cytologist, who should be subject to a strict process of auditing of diagnoses. (see also page 39, where you make this point very well)	No response required.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 41	If, under special circumstances (e.g. the Highlands?), a smaller population base is considered acceptable, it is essential that no compromise is made in the size, composition and quality of the staff and facilities available to that MDT. Personally, I would be even more radical and propose a population base of 2 million (as was present in the first version of the BAHNO report). Also, a definition of new cases must be rigid, so that units cannot claim that skin SCC and BCC are all part of their core head and neck workload, for example. Using a population base rather than pure numbers would, in my mind, be preferable therefore.	Agreed. These points are already covered; the population base quoted is, however, one million.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 43	"Each surgeon in the MDT should normally dedicate at least half of his or her time to head and neck cancer" – This statement must be reinforced and used as a yard stick for surgeon to committee themselves to a head and neck cancer service otherwise this will be a pious aspiration!	This is a recommendation, which should be implemented.
British Association of	Page 46	Do we really need a separate thyroid cancer MDT with an annual incidence of some 15 per million per year!	There does not have to be an entirely separate team, as long as the specialists are available.

Otolaryngologists, Head & Neck Surgeons		This may be interpreted as requiring a separate process with all of the resourcing? Thus diluting resources – money and staff – away from other MDT's!	
British Association of Otolaryngologists, Head & Neck Surgeons	Page 46	Middle of third paragraph Major surgery – please define! What is a specialised head and neck ward – also need to be defined!	The text is as clear as it needs to be about the scale of surgery envisaged at centre and local level, and the degree of specialisation: in practice such issues will be resolved within each Cancer Network.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 47	Last line last words – condone this recommendation -clinical psychologists etc	No response required.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 48	Dental Services – condone and highly recommended	No response required.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 48	The description of the role of the SLT needs to be expanded. [contrast with the detail on the role of the CNS] The first sentence is unclear re needing a high level of expertise over a year or longer. There is no mention of our key role in the mgt of SVR patients and the long term nature of this. Management of voice problems needs to be included. Assessment needs to be expanded on and include use of Videofluoroscopy and FEES. SLT has taken on the role in helping patients understand the nature and impacts of interventions particularly in relation to communication and swallowing. Counselling and support for patients and carers should be included. Also advising on alternative / augmentative methods of communication.	The text has been re-written. This section is about teams, not specific interventions. The section on the role of the various team members and their interactions has been substantially revised.
British Association of	Page 52	Increased concentration --- Should there be a recommendation that patients with symptoms need not necessarily be screened by	The text referred to is a summary of expected benefit, not a recommendation as such.

Otolaryngologists, Head & Neck Surgeons		head and neck cancer doctors, and only those patients who have or proven biopsy should be seen by head and neck cancer surgeons – thus increasing surgical time for some and increasing clinic time for others! Rationalising the service further!	
British Association of Otolaryngologists, Head & Neck Surgeons	Page 55	Radiotherapy, radiology and histopathology services are under particular pressure – And what is the solution! Why put this naked statement if it there is no commentary!	Sentence deleted.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 62	Communication skills – more should be commented on the desirability of the clinicians who should work with cancer patients!	This concern is covered by current text (see para 2 of informing patients).
British Association of Otolaryngologists, Head & Neck Surgeons	Page 64	Re videotapes should be given to patients. I would suggest "offered" rather than "given". In my experience some patients are reluctant to view the tapes at this stage.	Agreed. This amendment has been made.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 69	Careful assessment etc --- This is an ideal and can currently only be lip service to a seriously under funded and resourced cancer service! Are these desirable or essential!	This recommendation is consistent with evidence of weaknesses in current services. Quality of Life outcomes are important in this group and a priority for the development of head and neck cancer services. This recommendation is necessary to improve care.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 71	It would normally be the SLT not the dietitian who advises on consistencies of diet. The SLT working with patients to " restore speech" does not adequately describe what we do. Suggest something along the lines of – maximize pt's potential for recovery of speech, voice and swallowing and advise on strategies to assist the patient where appropriate.	Further clarification of the role of the Speech and Language Therapist has been added.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 71	A specialist anaesthetist – essential or desirable! Many hospitals have shared anaesthetists for the major cases!	Anaesthetic assessment. The sentence now reads: 'Patients who are to undergo surgery which will involve the airways should be assessed by an anaesthetist who works regularly with surgeons on the MDT'.
British	Page 71	It would normally be the SLT not the dietitian who advises on	This is covered in the revisions to this section.

Association of Otolaryngologists, Head & Neck Surgeons		consistencies of diet. The SLT working with patients to " restore speech" does not adequately describe what we do. Suggest something along the lines of – maximize pt's potential for recovery of speech, voice and swallowing and advise on strategies to assist the patient where appropriate.	This revision is accepted.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 76	– Head and Neck Dieteticians should be recognised as a specialists group rather than the use of generic dietetics.	The qualifications for dietetics involved in head and neck cancer work is defined in the part of the document that deals with the formulation of the MDT. It is clear that all members of the MDT have specialist roles in head and neck cancer. These are not intended to be 'general purpose' dietitians.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 76	I'm surprised [and think that SLTs may be a little insulted] that the suggestion laryngectomees train others to communicate has been included. This seems to be a recommendation of a Swiss study that focuses on teaching oesophageal speech. How relevant is this study to this report, given the majority of patients in UK are now offered SVR?	Reference to the Swiss study has now been removed, and the text modified.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 77	Imaging – CT Chest has shown to be an effective screener when major surgery is being undertaken and a more extensive Chest CT should be performed on patients who have a positive result!	The text here is a simple description of existing audits of practice. It is not felt necessary to elaborate further on the significance of these investigations. The primary message is one of some inadequacies in chest imaging which emphasise the need to develop and apply imaging protocols more reliably.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 80	What is minor surgery – please define! It's like easy ones and hard ones!	The thrust of this recommendation is quite clear. The detailed interpretation of that will be a matter for Network policies and for MDTs. It would not be helpful to attempt a detailed definition in this guidance.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 80	Sufficient funds to cover ---- Adequate funds for specialist services or the money should follow the patient! Page 80 Laser surgery. It would appear that laser surgery has now been accepted by the British establishment. (?) Page 80 Re Surgical voice restoration . Should this also mention that SVR should ideally be offered as a primary procedure.	The first part of the comments are dealt with in recommendations on Network commissioning. The developers have never seen themselves as part of the British establishment! We do not need to be drawn into making the 'ideally … ' qualifying comment. We have raised the need for SVR

		Page 80. Middle para. '…difficult in centres which deal with fewer than four cases per week'. I would add the word 'new' to cases, as head and neck workload includes a significant amount of work with recurrent disease.	as part of the range of provision. Reference to a specific number has now been removed.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 81	Brachytherapy – this should be specialist services and funded appropriately! As like chemotherapy! Page 81. Although chemotherapy is undeveloped in H&N compared to many tumour sites, the likelihood is that, in the lifetime of this document, it will acquire a greater and more evidence based place. It would be useful to acknowledge this by a short paragraph relating to chemotherapy as a separate item, rather than within Radiotherapy only.	The comment on funding has been addressed in the commissioning arrangements. The reference to the future use of chemotherapy is briefly touched on in the context of chemoradiotherapy in this section and is mentioned as a modality in its own right in the section on Advanced Disease. The problem is that current evidence for the effectiveness of chemotherapy and head and neck cancers is weak. It may well be that this is a growing role but if that is the case that will need to be based on solid evidence from well conducted studies. We have been concerned about the underlying evidence for treatments in head and neck cancer and have made a Key Recommendation urging more trials activity.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 82	Temoporfin (Foscan) has, I understand, been approved for use in a palliative loco regional control setting. To restrict its use to trials might be challenged ethically –perhaps use in centres after full MDT assessment would be more appropriate. Page 82 Re support for patients undergoing radiotherapy. There should be SLT review of patients with swallowing and voice problems in particular. Laryngectomees will need reviews of their valves pre, during and post radiotherapy.	The recommendation in the guidance is already qualified by the phrase 'unless there is reliable evidence of effectiveness'. We contend this is already covered and the role of the SLT is dealt with in a number of places in the document, notably Topics 2 and 5.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 83	Support very welcome in an essential area. Clinical researchers need recognition and time to produce work of quality which will impact on patient care. Too often, this is eroded by routine clinical duties.	This issue is now covered within the Key Recommendations in addition to the reference in this topic.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 85	Major centres report success rates in excess of 95% -- is this for flaps or patients!	This relates to flaps; the text has been clarified.

British Association of Otolaryngologists, Head & Neck Surgeons	Page 93	Bullet 1 – expand on this recommendation and discuss its implications – more patient deaths, failure of flaps etc! Patient's psychology or overall impression of a poor head and neck cancer service for head and neck patients!	The developers are not clear what point is being made.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 93	Bullet 2 – please explain this patient orientated service!	The developers are not clear what point is being made.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 94	Bullet 4 should include tracheostomy and swallowing problems specifically	It is not clear to which bullet point this refers.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 96	Plus or minus should be and or after!	Text has been re-worded.
British Association of Otolaryngologists, Head & Neck Surgeons	Pages 99– 02	Given that a high percentage of H&N patients have recurrence, this palliative care section does not go in to a great deal of detail. It would suggest that SLT support needs to be available so that patients can have ongoing assessments and advice regarding communication and swallowing. This will help patients make informed choices as well as provide support.	The section is intended to be complementary to the guidance for 'Improving Supportive and Palliative Care for Adults with Cancer', published in March. Text has been added, specifying ongoing assessment and advice from SLT; the point about informed choices and support has now been made in Anticipated Benefits.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 103	This page needs better scripting and editorial control " laryngectomy patients may require specialist help for a year or more" I would suggest "will" rather than "may" require specialist help. This should be from a Specialist SLT Many laryngectomees will require ongoing support – some for many years.	Some amendment has been made to the text.
British	Page	Chest x-ray annually!	Reference is now made to local clinical guidelines for

Association of Otolaryngologists, Head & Neck Surgeons	106	Re "surgical voice restoration is preferred". This needs to be stated more strongly. SVR should be available to all laryngectomees. Who should provide electronic voice equipment?	follow-up; this issue should be locally agreed. The text now reads: 'A full range of techniques, products and facilities should be available for voice rehabilitation and electronic larynx equipment should be provided for those who need it.' Local arrangements should be established in each network for the prompt provision, maintenance, and replacement of electronic voice equipment.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 107	First paragraph --- better to suggest a process rather than a woolly discussion! Then this process can be audited and future recommendation can be based on evidence!	There is no evidence for what the process should be. To be defined locally, and regularly audited (see Teams).
British Association of Otolaryngologists, Head & Neck Surgeons	Page 108	Rephrase second paragraph!	Please clarify what you have in mind.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 108	And distant metastases including the lungs (might be better!)	This has been re-worded for greater clarity.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 109	Most of these studies should have a date added when published! (Would add more meaning when being read!) Page 109 - Some of these studies don't seem terribly relevant. There are more up to date and relevant studies available. Re"patients with transport problems" – should this be "transit" rather than "transport".Suggests they haven't got a car!	These are fully referenced in the accompanying Research Evidence document (with the next draft). This has now been deleted.
British Association of Otolaryngologists, Head & Neck Surgeons	Page 110	There is more evidence to support hyperbaric evidence than quoted to improve osseointegration after radiotherapy. Question osseointegration has been introduced as a rehabilitative procedure – can we have evidence that this procedure is good and there is evidence, then will the head and neck service be funded for the "complete" rehabilitation of the oral/oropharyngeal cancer patients swallowing and speech, as well as cosmesis. The	This comment relates to the Evidence section. There is no specific recommendation about osseointegrated implants (with or without hyperbaric oxygen). The Evidence section has been revised. Full details about the evidence relating to osseointegrated implants are given in the Research Evidence, available at the second consultation.

		introduction here implies that all clinics should and must be osseointegrating all patients who are deserving! Not covered but an important sequelae of late radiation tissue damage. Can occur spontaneously or be precipitated by tooth extraction. Evidence for prevention by hyperbaric oxygen therapy. Teeth should not be removed without assessment and management, ideally through a maxillofacial or dental unit. Exactly where this fits I am unsure but it is a cause of major morbidity and cost.	
British Association of Otolaryngologists, Head & Neck Surgeons	Page 111	Why do we need evidence from Finland to support a Laryngectomme Club system! We have had a National Association of Laryngectomee Clubs in the UK for many decades --- why not ask NALC to give you evidence! Or is there really a need to have evidence for something that seems so obvious!	All identified evidence is considered for inclusion in the Research Evidence, available at the second consultation. There is no reason to suggest that the study quoted is not relevant or appropppriate.
British Association of Otolaryngologists, Head & Neck Surgeons	Pages 104 – 5	Local support team – not another team please, this can be coordinated from the HnN MDT	The text as written covers this point.
British Association of Otolaryngologists, Head & Neck Surgeons	Pages 110	Pilocarpine does not justify such a strong recommendation! It is seldom used in this country, never mind the USA or Europe where most of the initial work was conducted.	The text has now been re-worded.
British Association of Otolaryngologists, Head & Neck Surgeons	Pages 114	Resource implications – Budgetary responsibility who will purchase the TEP valves and the other used communication aids. TEP should be used dependant on patients needs rather than on one type of valve?	The preliminary economic review is available with the second draft.
British Association of Otolaryngologists, Head & Neck Surgeons	P26 3rd paragraph	Larynx (typo) Fibre-optic or rigid endoscopy is essential. Stroboscopic examination of the larynx is useful	Amendment made. Agreed. Amendment made. This is too much detail for the Background section.
British Association of	P27	This section is weak. Should mention wider patient and carer needs e.g. psychological /financial	There is always a balance to strike between providing sufficient detail within the background section to

Otolaryngologists, Head & Neck Surgeons		Head and Neck vulnerable group due to pre-morbid problems (refs attached)– evidence that social status, support, tobacco and alcohol addiction, depression etc affects outcome. Not just re. facial disfigurement also body image. Anxiety and depression goes undetected pre-treatment. No mention of sexual problems. No mention of pre-treatment QOL measures being taken to establish base-line and identify functional problems pre-treatment and use to target appropriate rehabilitation/interventions.	orientate the reader, and including too much material. Most of the points identified here are covered in the later text. New text has, however, also been added.
British Association of Otolaryngologists, Head & Neck Surgeons	P28	Speech and Language Therapy figures re. staffing and grading needed.	Not appropriate for the Background section.
British Association of Otolaryngologists, Head & Neck Surgeons	1A p30	Networks decide which hospitals provide diagnostic service. This is a big responsibility and needs to be done formally in consultation with trusts delivering present services. It may be that support staff needs will not be prioritised or considered as the networks tend to be medically dominated.	This is speculation; networks must decide how the services will be organised.
British Association of Otolaryngologists, Head & Neck Surgeons	2A p41	Again networks need to do this with full consultation as above. What happens if present centres with RT do not have 1m population?	Subject to local network negotiation.
British Association of Otolaryngologists, Head & Neck Surgeons	p43	Speech and Language Therapist with expertise in patients with head and neck cancer patients (not just after treatment)	Agreed. Further clarification of the role of the Speech and Language Therapist has been added.
British Association of Otolaryngologists, Head & Neck Surgeons	p47 & p52	These two sections could be put together -repetitive. The role of CNS is put in great detail but others in MDT possess and use these skills as well (SLT particularly). Many teams do not have CNS. This could be expanded section on p42 re. SLT skills rather than in posts within MDTs.	The text has been edited to remove repetition.
British Association of Otolaryngologis	Section 2 p.48	Re-word “over a substantial time.over a year “ -is ambiguous change to “demands a high level of expertise with significant postgraduate	This sentence has been amended. (It is about patient management, not training.)

ts, Head & Neck Surgeons		training. Re-word SLT role to "The SLT will be responsible for the assessment and management of communication and swallowing throughout the patient journey." Don't like term 'face-to-face' communication. This reflects broad scope of SLT intervention that it may be non-oral (using aids) and that intent may not be rehabilitative but maintenance or palliation. SLTs working with laryngectomy keep patients on indefinitely for management of SVR programme Pre-treatment assessment should identify problems with voice, speech and swallowing by presence of cancer and take base-line measures. Add SLT assesses literacy skills in preparation for alternative post-treatment communication, cognitive skills relevant to decision-making and informed patient choice.	The role of the SLT has been re-worded. This terminology comes from the recently-published 'Improving supportive and palliative care for adults with cancer'. What 'reflects broad scope of SLT intervention'? Not clear. This section of the guidance seeks to clarify the roles of the MDT members; every detail of what they actually do cannot be included. See above.
British Association of Otolaryngologists, Head & Neck Surgeons	p.49	'Professions allied to medicine' should be Allied Health Professions' 'Copies' of casenotes – should be actual notes. Copies not good practice.	Amendment made.
British Association of Otolaryngologists, Head & Neck Surgeons	p.50 Paragraph 3	Laptop computer 'used' should be 'completed'. Should aim for direct inputting to database for real time data capture at source. Typo 'be' missing before available.	The point is about using the form electronically, so that it is always as up to date as possible. Amendment made.
British Association of Otolaryngologists, Head & Neck Surgeons	p.50	'as quickly as possible' should be quantified.	Will depend on local circumstances.
British Association of Otolaryngologists, Head & Neck Surgeons	p.50	Should these be clinical or admin staff?	Will depend on local circumstances.
British	D p.58	Structure not just CNS - all care members of team including SLTs	Amendment made.

Association of Otolaryngologists, Head & Neck Surgeons		Process How will participation (other than attendance) be measured?	To be defined locally.
British Association of Otolaryngologists, Head & Neck Surgeons	E p59	And dedicated specialist head and neck cancer SLTs	A generic statement has been added to the resource implications.
British Association of Otolaryngologists, Head & Neck Surgeons	p.62	And sensitive to individual patients coping style (ref. De Leeuw 00 positive and negative effects of information, Miller 95-coping styles)	This is considered to be too great a level of detail for site-specific guidance, and is a generic issue for cancer patients; see 'Improving Supportive and Palliative Care for Adults with Cancer', published in March.
British Association of Otolaryngologists, Head & Neck Surgeons	P63-64 +5. p 70	Patients should have choice of whether to avail themselves of these options re meeting others. 2 papers suggest some patients do not cope with this well refs attached Resource implications for training patient visitors. Should be available to all H&N patients.	The wording 'option of' has been added.
British Association of Otolaryngologists, Head & Neck Surgeons	P65	Other refs re information-giving Stam 91, Stafford N, 2001, de Leeuw and de Graeff 00	See response to point above.
British Association of Otolaryngologists, Head & Neck Surgeons	P66	Additional ref. Re surgeons practice Nick Stafford 2001	This paper is a description of a survey of current practice; not included in the research evidence for this guidance.
British Association of Otolaryngologists, Head & Neck Surgeons	P70	Ditto above findings	See responses above.
British Association of	P71 paragra	For 'restore' read 'optimise' (not always possible to restore). Include voice, swallowing	See responses above.

Otolaryngologists, Head & Neck Surgeons	ph 2	Should be he/she	
British Association of Otolaryngologists, Head & Neck Surgeons	P78	Add access to specialist SLT and dietitian.	This point is broadly accepted and will be considered as part of a general review in the light of all the comments about the content of the Measurement section.
British Association of Otolaryngologists, Head & Neck Surgeons	P80 paragraph 5	SVR programme requires significant on-going personnel and equipment with resource implications. Requires dedicated budget for long-term patient support	This comment is returning to the funding theme which has been addressed.
British Association of Otolaryngologists, Head & Neck Surgeons	Paragraph 1 p82	Management of mouthcare is multi-disciplinary responsibility and account needs to be made of individual difficulties e.g. treatment approach/dentition etc.	This is a crucial issue. The Editorial Board has reviewed the existing text to make it more generally applicable.
British Association of Otolaryngologists, Head & Neck Surgeons	Paragraph 2	Include voice.	This comment has been made elsewhere and is accepted. The change will be made in the text.
British Association of Otolaryngologists, Head & Neck Surgeons	P83 final paragraph	Research components to jobs will have implications. Needs to be built in to all core members JDs.	Although outside the remit of this guidance such issues appear to be important in the implementation of the new Consultant Contract.
British Association of Otolaryngologists, Head & Neck Surgeons	D p92 paragraph 3	SALT– use recognised term – do not introduce 'swallowing' therapist.	The point is accepted, and the amendment made.
British Association of Otolaryngologists, Head &	Process p93	How will adequacy of surgery be measured? Add in audit of functional outcomes and audit of QOL measures	This comment is partially accepted. Audit of functional outcomes after surgery has now been added. However, 'audit of QOL measures' seems so vague as to be virtually meaningless; also, QOL at this point in the

Neck Surgeons			patient journey is more likely to reflect the extent of surgery than anything else. This has therefore not been included.
British Association of Otolaryngologists, Head & Neck Surgeons	P101	No reference to SLT and dietitian role in palliative care re. Nutritional and communication support	The aim of this section is to highlight interventions in the terminal care phase The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatment - Topic 6 becomes 'Aftercare, rehabilitation and support' - Topic 7 becomes 'Follow-up and recurrent disease' - Topic 8 becomes 'Palliative Care'
British Association of Otolaryngologists, Head & Neck Surgeons	Sec 8 p103	Problems with should include communication.	It is assumed that this is the same comment as The Royal College of Speech and Language Therapists. Therefore we offer the same response, i.e. that the sentence in question relates to tube feeding specifically. Communication is discussed further on (and now in more detail).
British Association of Otolaryngologists, Head & Neck Surgeons	Sec 8 p103 2nd paragraph	On-going support not just 'year or more'.	Some amendment has been made to the text.
British Association of Otolaryngologists, Head & Neck Surgeons	P105	More emphasis on linking and training community staff.	This is included in the discussion on the role of the CNS in the chapter on MDTs, and now cross-referenced.
British Association of Otolaryngologists, Head & Neck Surgeons	P106	SVR preferred but patient choice paramount. Add other communication aids should be available not just artificial larynx.	The text refers to 'a full range'. No amendment.
British Association of Otolaryngologists, Head &	P106 1st paragraph	Access to swallowing assessments of videofluoroscopy and FEES and nasendoscopy/rigid endoscopic exam of larynx.	Too detailed – these are not clinical guidelines.

Neck Surgeons			
British Association of Otolaryngologists, Head & Neck Surgeons	P109	Need more up to date refs re laryngectomy voice (Armstrong 01, Perry 03, Frowen see ref list).	The Perry paper post-dates the searches. The references given have been checked for relevance to the research questions. All the references used to support the guidance are included in the Research Evidence.
British Association of Otolaryngologists, Head & Neck Surgeons	General	Spelling of 'dietitian' incorrect throughout Different use of Speech and Language Therapist terms through document eg Speech therapist SALT Speech & Swallowing. Needs to be consistent and suggest Speech and Language Therapist (SLT) I am disappointed QOL assessment is not more prominent, particularly in pre-treatment stage to take base-line measurement, target appropriate intervention and inform patients on likely consequences of treatment proposed on both function and QOL See ch. 4.1 in BAOHNS effective Head and Neck Cancer Management 2003 (refs) by Simon Rogers and Kaye Radford Also more refs to this document in guidelines would be appropriate.	Spelling has been corrected. Agreed. This is now consistent (SLT throughout). There are a huge number of issues which could be subject to audit and measurement. A judgement has been made therefore to have a restricted list, but in order to reflect these concerns a sentence has been added to the end of the Background section as follows: 'The variety of issues that could be included is almost infinite and a wide range of additional issues could be monitored, some of which will have particular relevance to specific population groups or areas. Audit activity of this sort is valuable and the necessarily limited list given should not be regarded as complete.' All the references used to support the guidance are included in the research Evidence, available with the second draft of the manual.
British Association of Plastic Surgeons			This organisation was approached but did not respond.
British Committee for Standards in Haematology			This organisation was approached but did not respond.
British Dietetic	General	Need to standardise the spelling of "Dietician" as "Dietitian"	Spelling has been standardised.

Association		throughout the document 24, 65, 66, 69, 72, 87, 100	
British Dietetic Association	General	The written text is supported with evidence and can be made available on request	All the references used to support the guidance are included in the Research Evidence, available with the second draft of the manual.
British Dietetic Association	General	Huge financial implications on Cancer networks as funding for specialist head and neck dietitians will need to be increased to meet the recommendations laid out in the document	The preliminary economic review is available for the second consultation.
British Dietetic Association	General	This document is much needed to improve the overall management of head and neck oncology patients which can only be achieved in collaboration with each core and extended member of the MDT. The Dietitian is a core member of the MDT and at present there is much needed information to be included within this document to support the roles and responsibility of the Dietitian within this population group. Please refer to letter that has been sent to the editorial board by the British Dietetic Association	It is acknowledged that the references to the dietitian, and the role, required review. There have been extensive amendments and additions to the second draft of the manual to take account of this.
British Dietetic Association	General	Dietitian can be male or female. Throughout this document the dietitian is described as 'she', this will need to be corrected	It is believed that all the necessary amendments have now been made.
British Dietetic Association	General	Could the 'core' and 'extended' members of the multidisciplinary team be listed at the outset of the document	The developers believe that this would not be helpful, and that they are included in the appropriate section, i.e. Topic 2, Structure of services.
British Dietetic Association	General	The term "gastrostomy" " rather than "PEG" should be used in the document as many head and neck patients will not be suitable for PEG's and require alternative methods of placing a gastrostomy such as radiologically or surgically.	It is believed that this point is adequately covered in the revised draft, which now also includes a Glossary, defining both gastrostomy and PEG.
British Dietetic Association	General	Catering provisions for head and neck patients is not included in the document	This is now included.
British Dietetic Association	Page 3	Could the sentence "…permanent effects on organs…" read as "permanent effects on anatomical structures…"	This is Professor Haward's personal summary. Proposed amendment not accepted.
British Dietetic Association	Page 3	Could the sentence "Consequently, patients facing therapies…" read as "Consequently, patients facing treatment modalities…"	This is Professor Haward's personal summary. Proposed amendment not accepted.
British Dietetic Association	Page 3	Head & neck patients often with chronic histories of excessive alcohol intake and heavy smoking which can often lead to poor dietary habits. Could the sentence "People who present…..such as heavy smoking and alcohol consumption" read as "People who	This is Professor Haward's personal summary. Proposed amendment not accepted. Further detail is included in the background section.

		present….such as heavy smoking and alcohol consumption leading to poor dietary habits and risk of malnutrition.	
British Dietetic Association	Page 4	Could a section be included on the increasing and significant role of AHP's (specifically Dietitian, CNS and SLT), for the management of these patients as a 'core' member of the MDT and the need for resource allocation for such services.	Too much detail for the Foreword. Later in the text of the guidance, additional information has been included on the roles of the dietitian and the SLT. The text on the role of the CNS has also been revised.
British Dietetic Association	Key Recommendations	Each MDT should include a specialist dietitian, who will aim to optimise the patient's nutritional status to meet the nutritional needs by recommending appropriate interventions that are individualised and realistic for the patient to achieve. This needs to be co-ordinated within each MDT.	The wording of the key recommendations has been substantially revised, as has the text of Topic 2, which deals with Structure of services.
British Dietetic Association	Bullet point 3	The sentence "These include speech, language and swallowing services, dentistry, nutrition…" should read as "These include speech, language and swallowing services, nutrition and dietetic services, dentistry…"	The wording of the key recommendations has been substantially revised.
British Dietetic Association	Page 13	The sentence "Survival rates differ markedly according the site…" should read as "Survival rates differ markedly according to site.."	Amendment made.
British Dietetic Association	Page 15	The sentence "This is partly because many patients are already debilitated at the time of diagnosis…" should read as "This is partly because many patients are already debilitated and present with a poor nutritional status at the time of diagnosis:…"	This section of the background has been re-written.
British Dietetic Association	Page 17	"Weight loss which is a predominant symptom due to the combined effect of chewing and swallowing problems" should be included."	Weight loss is a consequence of chewing and swallowing problems, not the cause; no amendment proposed.
British Dietetic Association	Page 17	The sentence "…other symptoms may include pain on swallowing or problems with swallowing (dysphagia)" should read as "other symptoms may include……..swallowing (dysphagia) and weight loss".	See above response.
British Dietetic Association	Page 18	"Weight loss is a predominant symptom for oropharyngeal and hypopharyngeal carcinoma".	See response to point above.
British Dietetic Association	Page 20	Smoking increases requirements for antioxidants, thus further exacerbating the risk. *(reference available on request)*	Too much detail for service guidance.
British Dietetic Association	Page 20	This paragraph on diet needs to be reviewed to include: "Patients who present with chronic histories of excessive alcohol intake and heavy smoking often have poor dietary habits. Malnutrition can often arise when alcohol contributes a significant percentage of the individuals daily energy intake at the expense	The text has been revised to include reference to poor dietary habits.

		of their diet and may result in an inadequate intake and place the individual 'nutritionally at risk'."	
British Dietetic Association	Page 20	Early stage oral cavity carcinoma, at risk for second primary cancers, has a statistically significant deficiency in dietary sources of antioxidant nutrients. *(reference available on request)*	This is too much detail for service guidance.
British Dietetic Association	Page 20	Increased fruit and vegetable intake (5 portions a day) is associated with reduced cancer risk and is strongly recommended in preference to vitamin supplementation. *(reference available on request)*	The role of increased fruit and vegetable intake is already included.
British Dietetic Association	Page 24	Interventions such as gastrostomy placement is an integral component of a comprehensive palliative care package for patients with no or little oral nutrition. *(reference available on request)* As part of the MDT: It is the dietitians role to identify and inform patients who may benefit supportive nutrition with the aim of improving their quality of life during the palliative and terminal stage of their disease. This requires full discussion with the patient, carers and multidisciplinary team.	This is too much detail for the background section. These issues are covered in the appropriate sections.
British Dietetic Association	Page 24	The sentence " …..people can have difficulties with speaking, chewing and swallowing" should read as "….people can have difficulties with speaking, chewing and swallowing. The problems faced by patients to eat and drink may impact on their oral intake and increase their risk of developing malnutrition".	Agreed. A further sentence has been added to cover this point.
British Dietetic Association	Page 29	This sentence "…or pan should also arouse suspicion". should read as "…or paan should also arouse suspicion. Unexplained weight loss of greater than 10% over 6 months or more than 5% in one month is likely to highlight the patient as clinically at risk and should therefore also arouse suspicion in the urgent referral setting."	Amendment made. The urgent referral criteria are taken verbatim from the DH criteria. These are currently being revised by NICE.
British Dietetic Association	Page 36	Early nutritional screening to identify those patients who would benefit an assessment from a dietitian	This issue is dealt with in Topic 4; Pre-treatment assessment.
British Dietetic Association	Page 37	Audit the use of the nutritional screening tool and referrals made to the dietitian for patients who have been screened and may benefit from a dietetic assessment	This issue is dealt with in Topic 4; Pre-treatment assessment.
British Dietetic Association	Page 37	Correct nutritional deficiencies and prevent weight loss	This issue is dealt with in Topic 4; Pre-treatment assessment .
British Dietetic	Page 38	It is important that each MDT within a Network should be led be a	A sentence has been added to clarify this.

Association		designated senior clinician	
British Dietetic Association	Page 39	The sentence "….not necessary for every H&N Ca MDT to include all types of specialist, it is important that all the skills required to deal with the range of patients treated by each MDT are available among its members" – why? Perhaps not all types of specialist are needed for each individual patient but if listed as part of MDT surely each MDT needs each specialist?	This refers to every specialism required; the specialists in whom these skills are vested may vary.
British Dietetic Association	Page 40	The bullet point "Dietitian with a 'specialist interest' in patients with head and neck cancer" should read as "Specialist head and neck oncology dietitian, with the expertise and experience to assess, identify, evaluate and monitor the ongoing nutritional needs of the patients.	The bullet point now reads 'dedicated dietitian' and a paragraph describing the role of the dietitian has been added.
British Dietetic Association	Page 41	Large numbers of head and neck patients require gastrostomy insertion as an integral part of their nutritional management. There needs to be a co-ordinated service to ensure careful patient selection and appropriate gastrostomy placement. Head and Neck surgeons and oncologists need to liaise closely with gastroenterologists, radiology and general surgeons. Time will need to be ring-fenced in surgery and Endoscopy, with a secondary service available in radiology, for placement of feeding tubes. These patients need to be established onto gastrostomy feeding and monitored closely to prevent any complications associated with morbidity and mortality. Other services such as nutrition nurses are also needed to ensure patients are well informed about tube aftercare. *(references available on request)*	The following text has been added in the section on extended team members: 'Gastroenterologists, radiologists and GI surgeons for PEG or other enteral feeding tube placement and support.'
British Dietetic Association	Page 41	• Gastroenterologist for percutaneous endoscopic gastrostomy placement • Radiologist for radiologically placed gastrostomy / nasogastric / nasojejunal tubes • General Surgeon for open gastrostomy / jejunostomy placement	See response above.

		• Nutrition nurse for enteral feeding tube care • Occupational Therapist	
British Dietetic Association	Page 42	Specialist Head and Neck Dietitian National documents highlight the need to include the dietitian at every stage of the patient's journey. Nutrition has been shown to be the second most important long-term prognostic factor in Head and Neck Oncology. Many of the treatments for Head & Neck cancer have an adverse impact on nutritional status. Even patients who are disease-free post treatment may present with late side effects from both surgery and radiotherapy, which may impact on their oral intake and increase their risk of developing malnutrition. Dietetic input throughout the patient pathway is needed in order to: • Assess patients' nutritional needs • Evaluate how different treatments will impact on a patient's nutritional status • Recommend the most appropriate short/long term nutritional interventions • Negotiate specific practical dietary changes to meet nutritional and/or therapeutic goals • Assist individuals to undertake dietary change As part of the multidisciplinary team, the dietitian also: • Contributes nutritional expertise in developing protocols and policy relating to nutrition, and the auditing of these • Provides information, expert opinion or advice on current thinking / evidence based / best practice in nutrition • Develops clear, up-to-date and practical written information for patients on relevant aspects of diet or nutrition.	A paragraph describing the role of the dietitian has been added.
British Dietetic Association	Page 43	The sentence "..:experts from MDT should therefore offer out reach service…" Extremely relevant but needs to be adequately resourced as often there is variable or no dietetic service for cancer centres to link to because of under resourced dietetic services. This will need	Agreed. This is an issue for individual networks to resolve, depending on local circumstances.

		addressing and supporting at Network level to ensure there are strategies in place for collaborative working.	
British Dietetic Association	Page 43	This section mentions "…consult the CNS for expert advice on issues such as managing patients with ….gastrostomies…" "The dietitian is also key professional that other professionals should be able to consult regarding the suitability and method of gastrostomy placement and overall management for enteral tube feeding."	This section has now been substantially revised, and also includes a section on the role of the dietitian.
British Dietetic Association	Page 45	The sentence "…distinctive and valuable perspective; the participation of the clinical nurse specialist and members of professional allied to medicine should be regarded……" should read as "distinctive and valuable perspective; the participation of the clinical nurse specialist, dietitian and speech therapist should be regarded as essential to the function of the team".	Agreed. Amendment made.
British Dietetic Association	Page 48	Appropriate nutrition and dietetic service provision for head and neck units will provide the anticipated benefits: (See section 3 Anticipated benefit) Benefit to the patient • Early identification of patients at risk of / or developing malnutrition who will benefit an assessment by a specialist dietitian • Patients will have access to an efficient, effective, high quality dietetic service, which will contribute to overall clinical outcomes • All patients who need it will receive the specialist support and advice they need to optimise their nutritional status and correct nutrient deficiencies, minimise the risk of malnutrition-related morbidity and mortality, resulting in improved functional and quality of life outcomes Benefit to Head and Neck Units • Cancer Centres will meet National Guidelines • Regular training and education of other members of the multidisciplinary team on aspects of nutrition in order to ensure consistent information is given to patients, and to ensure team members are aware of current advances and changes in practice. Education on nutrition is required at	Text has been added to expand on the benefits provided by various team members. New text inserted, as follows: 'Involvement of specialist dietitians in the MDT can improve outcomes by enhancing awareness of the importance of nutritional issues among care providers and by improving the nutritional status of individual patients through appropriate interventions. This both helps patients to cope with their treatment and its aftermath, and reduces the risk of complications.'

		all levels, from pre and post-graduate training, through to induction sessions for new members of staff • Nationally there is an urgent need for high quality research within the field of Head and Neck nutrition. There is also a dearth of evidence-based practice or protocols currently available. The above cannot be addressed effectively or efficiently in under resourced services without specialist dietitians.	
British Dietetic Association		Limited number of specialist head and neck oncology dietitians *(Can provide figures on request)*	Please supply the figures.
British Dietetic Association		• Availability of sufficient numbers specialist Dietitians to handle the specific roles and responsibilities described in this manual".	Dietitians have been added.
British Dietetic Association	Page 55	• Evidence that each patient has been referred to the relevant member of the multidisciplinary team • Evidence that nutritional issues for each patient have been identified and treated appropriately.	Not appropriate for this section.
British Dietetic Association	Page 55	Many more specialist head and neck dietitians are required to be included in all MDT's at cancer centre's / units. Dietitians' with specific remit of oncology or home enteral tube feeding within the network (acute and primary setting) to liaise with the cancer centre. (*further information available on request).*	This issue is covered in the economic review, available at the second consultation.
British Dietetic Association	Page 56	A nutritional screening tool should exist for all newly diagnosed head and neck oncology patients to identify malnutrition and those at risk of developing treatment related malnutrition.	This is too detailed for service guidance; it is not necessary to describe how nutritional assessments are performed.
British Dietetic Association	Page 58	The sentence "…patients should be given realistic and accurate information" should read as "patients should be given realistic expectations and accurate information…"	Patients cannot be given 'expectations'. No amendment proposed.
British Dietetic Association	Page 59	Any pre treatment interventions that may be required; pre treatment supportive nutrition; prophylactic gastrostomy placement	This point has been dealt with in the revisions to Topic 4, Pre-treatment assessment and management
British Dietetic Association	Page 59	Patients who have been nutritionally screened and identified as clinically at risk should be referred to a specialist head and neck dietitian at the point of diagnosis.	This point has been dealt with in the revisions to Topic 4, Pre-treatment assessment and management
British Dietetic Association	Page 59	It is the dietitians and SLT's role to fully inform the patient about the impact of different treatment options in the short / long term on	This point has been dealt with in the revisions to Topic 4, Pre-treatment assessment and management.

		their ability to eat and drink.	
British Dietetic Association	Page 60	The patient will be better informed about their nutritional treatment options, thus supporting the consent process.	No response required.
British Dietetic Association		Both the NCA and Face to Face also suggest that dietitians are appreciated for their support and information giving. Additionally, the need for specialist dietitians working in head and neck oncology was identified by patients.	This is simply a summary of key evidence.
British Dietetic Association	Page 61	NCA and Face to Face highlighted the following regarding Dietetics and food provision: Prior and during treatment several respondents mentioned: • Receiving varying levels of dietetic advice and support. Several people had found their consultants were simply not interested in this area although it was causing them significant difficulties. All felt that this was a very important area of care and for most it was not systematically or well provided. • Their eating difficulties being compounded by the poor quality of the food available in the hospital and / or it being unsuitable for their needs • Highlighted the need for specialist advice, his surgeon said he could do nothing about it	These issues are dealt with in other parts of the guidance.
British Dietetic Association	Page 62	Both the NCA report and Face to Face note that the role of the specialist dietitian is not recognised or well provided to support the patients ongoing nutritional needs.	These issues are addressed in the revisions under Topic 4, Pre-treatment assessment and management
British Dietetic Association	Page 62	Hospitals should provide appropriate texture modified diets to meet the requirements for head and neck patients. This may include soft and puree options and additional sauces/gravy at meal times and options for meal replacement snacks throughout the day.	This is just too detailed for service guidance
British Dietetic Association	Page 63	• Availability of written information for patients about members of the MDT and their roles during the patient pathway • Written protocols and guidelines for the nutritional management of head and neck patients in the network • Written protocols and guidelines, agreed by all Head &	These are helpful suggestions and have been reviewed against the original text – for both Topics 3 and 4. See new version.

		Neck MDT's in the network for the placement and management of gastrostomy tubes. • Availability of time and clinic space in out patient settings for each member of the MDT for consultations with patients / carers • Contract specification for external catering providers at each head and neck unit / centre • Availability of specialist head and neck dietitians or access to education and training from specialist dietitians for general dietitians	
British Dietetic Association	Page 64	• Audit of catering service provision for texture modified diets against guidelines for national descriptors. (*reference available on request)* • Patient satisfaction survey	These are helpful suggestions and have been reviewed against the original text – for both Topics 3 and 4. See new version.
British Dietetic Association	Page 64	• Patient satisfaction with food provision • Access to specialist dietitians to support patients • Quality of life	These are helpful suggestions and have been reviewed against the original text – for both Topics 3 and 4. See new version.
British Dietetic Association	Page 64	• Many more specialist dietitians • Development of national nutritional screening tool for head and neck oncology patients • External catering provide texture modified diets at cancer centre and units	Resource implications are amplified in the next draft. Only the larger cost impact issues are addressed.
British Dietetic Association		Useful information and references, however doesn't seem to have been written or structured like the rest of the document.	This presumably refers to the nutritional assessment summary in the Evidence. This is similar in approach to a number of descriptive accounts of evidence; it is felt to be useful to include these in the main manual narrative rather than just in the Evidence Review.
British Dietetic Association	Page 65	The sentence "…dietitian who can initiate action to remedy deficiencies". Should read as "Nutritional screening of all head and neck patients should be undertaken to identify those who should be referred to the specialist dietitian, who can assess the patients nutritional needs and evaluate how different treatments will impacts on their nutritional status, to recommend the most appropriate short / long term nutritional intervention. E.g. the dietitan should assess the patient for prophylactic placement of gastrostomy tubes" *(reference available on request)*	The comment invites us to go into more detail than is appropriate. However, the sentence beginning 'The nutritional status of the patient' now reads: The nutritional status of the patient should be assessed by a dietitian who can initiate action to remedy deficiencies, and recommend the most appropriate short and long term nutritional interventions and support during treatment'.

British Dietetic Association	Page 66	The dietitian is a core member of the MDT and should be included at every stage of the patients pathway, including decision making (reference available on request) The sentence " Appropriate members of the MDT….clinical nurse specialist and speech therapist, should discuss…" should read "Appropriate members of the MDT….clinical nurse specialist, dietitians and speech therapist, should discuss…"	This comment is agreed and the text has been revised accordingly.
British Dietetic Association		This heading should read as "Preparation for treatment effects on nutrition and swallowing"	The title of the short section now reads: 'Preparation for treatment effects on speech, nutrition and swallowing'
British Dietetic Association	Page 66	The sentence "A dietitian should discuss…." Should read as "A dietitian should evaluate the impact of surgery, radiotherapy and chemoradiotherapy on the patients nutritional status and ability to eat and drink during and after treatment, and ensure that the patient is fully informed and has realistic expectations. The dietitian should explain interventions such as nasogastric, nasojejunal and gastrostomy placement, supported by written information for both patient and carers. Patients should be encouraged with oral nutrition, unless otherwise indicated and supported by the dietitian to negotiate specific practical dietary changes to meet nutritional and/or therapeutic goals, as well as to assist patients to undertake dietary change with the overall aim of maintaining their nutritional status."	The proposed addition to the text is too detailed for service guidance. It is more appropriate for a detailed clinical guideline.
British Dietetic Association	Page 67	(Also refer to Section 2B: Anticipated Benefit) • Patients will have access to an efficient, effective, high quality dietetic service, which will contribute to overall clinical outcomes • All patients who need it will receive the specialist support and advice they need to optimise their nutritional status and correct nutrient deficiencies, resulting in improved functional and quality of life outcomes • Patients will have an improved understanding of the impact of different treatment options on their ability to eat and drink and will be better informed about their nutritional treatment options, thus supporting the consent process	It is accepted that the list of Anticipated Benefits did not say enough about the benefits before, during and after treatment of careful early assessment and decision making involving a range of disciplines including CNS, dietitian and speech and language therapist. An additional paragraph has been drafted in the Anticipated Benefits section to cover this point.

		• Early nutritional assessment will allow proactive nutritional management to improve the patients nutritional status and allow them to tolerate more intensive treatment • Patients requiring enteral feeding at home will be discharged safely and effectively, with adequate support, training and preparation (reducing the likelihood of readmission for feeding-related complications • Cancer centres will meet national guidelines	
British Dietetic Association		This title should be changed to Nutritional Intervention, under the title of nutritional assessment it then mentions PEG's. This is referring to the feeding of patients rather than assessment. Overall, this section needs to be re-written in the context of specialist dietetic input during treatment and not assessment, as this should be covered previously.	This is accepted.
British Dietetic Association	Page 68	The dietitian is key to provide appropriate and timely nutritional support that has shown to: ▪ Correct nutritional deficiencies and prevent weight loss ▪ Improve patients' nutritional status to allow them to receive more intensive treatment ▪ Minimise the risks of malnutrition-related morbidity and mortality ▪ Reduce the risk of developing post operative complications ▪ Prevent treatment interruptions and possible hospitalization ▪ Maximise patient motivation to improve overall quality of life *(References available on request)* • Education and support for patient and team members	An addition has been made in the Anticipated Benefits section to try and address the benefits from this part of pre-operative assessment and management. Text has been added to reflect these benefits; however, this amount of detail on the role of the dietitian would create an imbalance (or require that the whole document were considerably extended to do equal justice to other professionals throughout).
British Dietetic Association	Page 72	• Nutritional screening tools at each cancer centre and unit • Availability of more specialised dietitians • Time will need to be ring fenced in surgery and Endoscopy, with a secondary service available in radiology, for placement of feeding tubes	This topic within the document is undergoing a number of revisions. The Measurement section will be revisited and where necessary expanded. It is not, however, felt that the specific suggestions here fit well with the current focus of the measurements. Other measures will be able to pick up the underlying concerns here.
British Dietetic	Page 72	• Evidence for waiting times for gastrostomy placement in	The suggested additions to the Measurement section will

Association		surgery, endoscopy and radiology • Evidence for referrals made to the dietitian • Audit of minor and major complications with different methods of placing feeding tubes • Evidence of patients who have eating and drinking problems are seen by a dietitian and SLT. • Audit of patients not referred to the dietitian and who were admitted for feeding related complications during treatment • Evidence of audit for measurable nutritional outcomes • Evidence of audit for QOL issues relating to alternative feeding methods	be looked at when that section is revised. Many appear to be at too great a level of detail for service guidance but do raise issues which we may need to reflect in the Measurement section.
British Dietetic Association	Page 74	• Patient satisfaction survey • Assessment of patients to identify the suitability for the method of gastrostomy placement • Network wide protocols and guidelines for methods of placing gastrostomy tubes to reduced morbidity and mortality • Reduced complications with surgery, radiotherapy and chemotherapy relating to nutritional issues	As above.
British Dietetic Association		• More specialist head and neck oncology dietitians • Collaborative working with gastroenterologists / radiologists • Ring fenced time in surgery, endoscopy and radiology off gastrostomy tube placement	As above.
British Dietetic Association	Section 5	Psychology - A more realistic interpretation of quality of life in terms of food intake should be attempted for patients - limited food choice, textures, reduced pleasure from eating and drinking, risk of very slow return to oral feeding, etc	Further text has been added about eating difficulties, and their longer-term implications, in the new draft of the manual. See also the restructured Topic 6, Aftercare and Rehabilitation.
British Dietetic Association	Page 75	The sentence “patients should be encouraged to talk through any issues ……with their SALT or CNS….” Should read as patients should be encouraged to talk through any issues ……with their SALT, CNS or Dietitian….” The dietitian also remains in close contact with the patient and is an appropriate member of the team to discuss concerns highlighted by the patient regarding treatment options.	This point has been taken into account in an extension of the relevant paragraph.
British Dietetic		This should read as “*Support for patients undergoing surgery*	The heading now reads: 'Support for patients

Association		*and/or radiotherapy"* as there is no mention of support during surgery.	undergoing radical therapy', and the text has been appropriately broadened.
British Dietetic Association	Page 78	This should also include some information about the effects on surgery causing problems with eating and drinking, swallowing etc *(References available for effects of surgery / radiotherapy and nutrition on request)* The sentence "….how to minimise their impact, and how long they may be expected to last". Should read as ""….how to minimise their impact, and how long they may be expected to last. The dietitian should play a key role in providing this information".	See previous comment.
British Dietetic Association	Page 78	The sentence "Patients should have access to a specialist oncology dietitian.." should read as "Patients should have access to a state registered dietitian specialising in head and neck oncology"	The sense of both the current text and this comment are clearly the same. It's a case of determining which form of words is the most appropriate to use. The context of dietetic support in radiotherapy centres is probably handled differently in different locations, particularly depending on whether it is a specialist and isolated hospital or part of a larger complex. The sentence has been amended to read 'Patients should have access to a specialist oncology dietitian, who would liaise closely with their counterparts in the patient's local support team'
British Dietetic Association	Page 79	Having a MDT audit schedule, set annually, would be good to enable everyone to contribute & be aware of what others are up to. Would promote larger scale audits and possibly lead to research possibilities. This would need to be supported by the network	The comment on research emphasises links to the National Cancer Research Network. The NCRI Clinical Study Groups are our key focus for the development of new studies in head and neck cancer. Potentially these can cover all aspects.
British Dietetic Association	Page 79	Audit and research relating to nutrition in head and neck oncology is fragmented and currently there is only a limited amount being carried out. Nationally there is an urgent need for high quality research within the field of Head and Neck nutrition. The limited number of specialist head and neck oncology dietitians and demand for nutritional support in this population group needs to be addressed to allow dedicated time for much needed audit and research.	See response to point above.
British Dietetic Association	Page 80	Early nutritional assessment will allow proactive nutritional management to improve the patient's nutritional status and allow them to tolerate more intensive treatment.	A reference has been added to the previous topic (Pre-treatment Assessment), where this issue is discussed.

British Dietetic Association	Page 80	Complication rates in head and neck patients with greater than 10% weight loss have a high incidence of between 10 – 20% *(reference available on request)*	This point is covered in Topic 4 and will be referenced in the Evidence Review.
British Dietetic Association	Page 81	Radiation and chemotherapy both cause acute and late problems with eating and drinking. Approximately 80% of patients undergoing radiotherapy experience such problems and may lose up to 10% of their body weight. During chemotherapy and radiotherapy, dehydration and severe weight loss may occur if nutritional support is inadequate. This can lead to interruption of treatment and subsequent reduction in tumour control and overall survival. *(References available on request)*	See response above
British Dietetic Association	Page 81	Nutritional parameters such as weight changes can be used as a predictor for outcomes. Patients weight should be monitored from the point of diagnosis, before and after treatment and at every out patient appointment attended thereafter.	This is too great a level of detail and could be part of the clinical protocol within the individual units.
British Dietetic Association	Page 85	NCA report highlighted: • Their eating difficulties being compounded by the poor quality of the food available in the hospital and / or it being unsuitable for their needs	The paragraph on dietetic support has been extended to read as follows: 'There should be specialist dietetic support on wards where patients with head and neck cancer are nursed. The dietitian, ward nurses and specialist support staff should work with catering services to ensure that high quality food is provided in a form that meets the individual's requirements.' In addition, a paragraph has been added to the evidence section describing the findings of the NCA report on this point.
British Dietetic Association	Page 87	This should read as ""…access to a CNS, specialist and experienced head and neck dietitian…….	The comment is accepted and the change has been made.
British Dietetic Association	Page 87	This should read as " Facilities for all enteral feeding tube placement (NG, NJ,PEG, RPG and open procedures, with adequate support in enteral feeding clinics and the primary setting for patients who require these forms of feeding.	This wording is too detailed for the guidance. However, the bullet point covering this point has been re-drafted to read as follows: 'Facilities for a range of forms of enteral feeding (including nasogastric tube and gastrostomy), with adequate support, for patients based in hospital and the community who require these forms of feeding. A bullet point has also been added in the measurement section for Topic 6, After-care and rehabilitation, as

			follows: 'Systems for provision of specialised advice and assistance at any time for patients in the community who rely on tube feeding.'
British Dietetic Association	Page 88	• Contract specification for external catering providers at each head and neck unit / centre	The idea that the particular needs of food preparation for these patients should be part of the contract specification is clearly a relevant issue and is accepted. A bullet point has been added.
British Dietetic Association	Page 88	• Evidence of patients weight from the point of diagnosis at each MDT clinic thereafter • Use of agreed guidelines for the use of prophylactic gastrostomy tube placement in head and neck patients	There are a huge number of issues to do with the organisation of care which could be subject to audit and measurement. The published list could be elaborated almost indefinitely. The developers have tried to highlight the principal issues. It is quite clear that these are not intended to cover every possible area of care which could be audited. A decision in the end has to try and emphasise a manageable list of identified topics in order to help Cancer Networks and head and neck MDTs to identify ways in which they can measure the impact of their developing services. Many of the additional suggestions in these comments are relevant, yet cumulatively would be excessive. A judgement has been made therefore to have a restricted list, but in order to reflect these concerns A sentence has been added to the end of the Background section (where audit is discussed) which addresses this issue. It reads as follows: 'The variety of issues that could be included is almost infinite and a wide range of additional issues could be monitored, some of which will have particular relevance to specific population groups or areas. Audit activity of this sort is valuable and the necessarily limited list given should not be regarded as complete.
British Dietetic Association	Page 89	• Audit of morbidity / mortality associated with enteral feeding tubes • Audit of patients admitted to hospital with dehydration and malnutrition • Audit of impact with enteral feeding tubes on QOL	See response above.

		• Audit the use of the use of prophylactic gastrostomy tube placement • Audit of catering provision	
British Dietetic Association		The MDT should be defined and include the dietitian	It is, and it does.
British Dietetic Association	Page 91	Palliative placement of NG and gastrostomy tubes for symptom control	This is a palliative intervention – not appropriate for this section.
British Dietetic Association	Page 92	• Availability of services for gastrostomy placement as previously defined	The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatment - Topic 6 becomes 'Aftercare, rehabilitation and support' - Topic 7 becomes 'Follow-up and recurrent disease' Topic 8 becomes 'Palliative Care'
British Dietetic Association	Page 92	• Evidence that a Specialist dietitian has seen the patient to discuss nutritional support for symptom control as part of the MDT	The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatment - Topic 6 becomes 'Aftercare, rehabilitation and support' - Topic 7 becomes 'Follow-up and recurrent disease' - Topic 8 becomes 'Palliative Care'
British Dietetic Association	Page 93	• Survival rate of patients with artificial nutritional support • Morbidity and mortality of patients with gastrostomy tubes	The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatment - Topic 6 becomes 'Aftercare, rehabilitation and support' - Topic 7 becomes 'Follow-up and recurrent disease' - Topic 8 becomes 'Palliative Care'
British Dietetic Association	General	Nutritional support for dying patients – Gastrostomy is not a new surgical intervention and can be appropriate in certain contexts. Should not be dismissed as "rarely appropriate". This section needs to be re-written	The final sentence has now been deleted.
British Dietetic Association		Suggest the title should be changed to "Management of nutritional issues during the palliative and terminal stages"	This has been changed to: Nutritional support
British Dietetic Association	Page 96	The paragraph should read as: Patient's ability to consume oral intake can be severely restricted or eliminated due to the progressive nature of the disease causing	The text has been amended as follows: 'The principles of management for patients whose tumour interferes with swallowing are similar to those for

		mechanical obstruction and dysphagia. Additionally, the metabolic changes caused by tumour induced cancer cachexia may lead to a significant weight loss. The dietitian should negotiate the aims of nutritional support with the patient and provide them with realistic expectations of the nutritional goals. Enteral nutritional interventions such as NG and gastrostomy placement should be carefully considered for symptom control.	patients with airway obstruction (see above). A dietitian should discuss nutritional support with the patient.'
British Dietetic Association	Page 96	Nutritional support and symptom control	The benefit is symptom control (already included) not nutritional support.
British Dietetic Association		Can be provided on request	No response required.
British Dietetic Association	Page 96	Evidence of MDT discussion with patient / carer to determine risk v benefit of artificial feeding The role of the dietitian in palliative care, a key aspect to address the quality of life issues related to oral and artificial feeding	This is about the general functioning of the MDT – not appropriate.
British Dietetic Association	Page 97	Audit of tracheostomy and gastrostomy rates and complications in patients with advanced cancer	This has been deleted – a consequential amendment following other amendments to the text.
British Dietetic Association	Page 97	Nutritional outcomes for quality of life	What is a 'nutritional outcome' for quality of life?
British Dietetic Association	General	Problems with eating and drinking are not just short term whilst they recover from treatment.	The text now reads: 'Most are likely to have problems with eating and drinking and a substantial proportion have to cope with tube feeding (usually gastrostomy). These patients often live alone and need a high level of supportive care'.
British Dietetic Association	General	Gastrostomies are not a new surgical intervention. There is mention of the rehabilitation plan but nothing in relation to nutritional support. Eg….enteral feeding, transitional feeding to) , texture modification. A section needs to be included	The text on nutritional support has been substantially re-drafted.
British Dietetic Association	Page 98	The sentence "Most likely…….cope with feeding tube,…." Should read as "Even patients who are disease free post treatment may present with late side effects from both surgery and radiotherapy, which may impact on their oral intake and increase their risk of developing malnutrition and thus require nutritional support with artificial feeding for symptom control."	See response to point above.
British Dietetic Association	Page 98	A sentence at the end of the paragraph " …rehabilitation services is therefore required" to read as "…..is therefore required. Re-introduction of oral diet is a priority for this patient group.	The amendment suggested is not clear.

		Collaborative working between the specialist dietitian and speech therapist is crucial for patient motivation to provide a safe and effective weaning programme for enteral feeding, transitional feeding and texture modification. It is essential that good communication and close liaison between the acute and primary setting is also established both within and between these specialities.	
British Dietetic Association	General	Does not reflect the role and importance of the dietitian for this population group. This needs to be addressed.	A paragraph has been added under 'responsibilities of MDTs' about the role of the dietitian.
British Dietetic Association	Page 99	The sentence "….to ensure that sufficient numbers of appropriately trained staff…. Should read as " …to ensure that sufficient numbers of specialists (Dietitians and SLT's) are available in the hospital and community setting".	Not accepted. The existing statement is much broader.
British Dietetic Association	Page 100	The specialist head and neck oncology dietitian should be referred all patient at risk of malnutrition or whose primary treatment will impact their ability to eat and drink. Prophylactic gastrostomy placement and establishing the patient in the hospital setting for discharge with home feeding and liaising closely with community dietitians to ensure continuity of care is of paramount in view of the increased number of head and neck patients requiring home enteral nutrition *(reference available on request)*	Reference to the dietitian has now been added.
British Dietetic Association	Page 101	• ….particularly delayed effects of radiotherapy, surgery and chemotherapy) • Identification and treatment of patients who need additional support with functional or psychological problems (e.g.eating and drinking, altered body image)	Reference to radiotherapy specifically has been removed. Text amended.
British Dietetic Association	Page 102	To provide the patients with specialist advice from a dietitian in order to achieve the main aims of a follow up clinic, the dietitian is a key attendee at the following head & neck clinics: • Combined radiotherapy clinic • Head and neck oncology clinics for individual specialities It is recommended that a dietitian should also attend the following clinics that are recommended for the management of head and neck oncology patients:	Local policies to be agreed.

		• Videofluroscopy / Fibreoptic Endoscopic Evaluation of Swallowing clinics • Enteral feeding / PEG clinic	
British Dietetic Association	Page 102	It is also imperative that the patient retains contact details for their dietitian. The sentence "…Patients can be discharged…….details for their CNS and SALT…" should read "Patients can be discharged …details for their CNS, Dietitian and SALT…"	The text is now amended.
British Dietetic Association	Page 103	Collaborative working between the dietitian and the SLT to increase patient motivation and increase functional outcomes	It is assumed that members of each team do work collaboratively.
British Dietetic Association	General	There is evidence to support this section relating to the intervention of the SRD, prophylactic gastrostomy placement outcomes etc and will be provided in the near future. There needs to be a section included for nutrition	No response required. Evidence included in earlier sections of the manual.
British Dietetic Association	Page 108	• Audit of time taken for patients dependant on artificial feeding to consume full oral intake and maintain nutritional status • Audit of functional outcomes with oral nutrition in head and neck patients	This is too detailed for service guidance.
British Dietetic Association	Page 109	• Patient motivation with support from the dietitian for re-introduction of oral intake • Functional outcomes with eating and drinking • Improved patient quality of life	This is too detailed for service guidance.
British Dietetic Association		• Many more specialist dietitians	The preliminary economic review is available with the second draft.
British Medical Association			This organisation was invited to comment but did not respond.
British National Formulary (BNF)	Key recommendations	There is no mention of pharmacists' role in the head and neck cancer multidisciplinary team, even as an 'extended team member'. Surely pharmacists can have quite a major role to play in pharmacotherapy decisions for these patients and should be included as part of the team.	This point will be considered in the review of the text following the second consultation.
British National Formulary (BNF)	Key recommendations	Pharmacists should be mentioned when discussing local support teams for outpatient treatment and long term support. Pharmacists may have an important role in offering support following hospitalisation.	This point will be considered in the review of the text following the second consultation.
British National	Page 20	There is mention of the higher rates among people from South	There are a number of references to lifestyle factors in

Formulary (BNF)		Asian, India, Pakistan, and Bangladesh. Is this related to diet / lifestyle / genetic factors? On page 24 it states specifically that Cantonese-style salted fish increases risk – Can anything specifically be attributed to the risk in these other countries?	the background section and the section on Referral.
British National Formulary (BNF)	Page 20	States: *'Public awareness of oral cancer is low. Where people have heard of such cancer, they are more aware of smoking than of any other risk behaviours'* – What are these other risk behaviours?	This sentence has now been removed.
British National Formulary (BNF)	Page 23	*'Skull base cancers….treatment for these cancers is particularly challenging.'* Why is the treatment challenging?	Skull base tumours are particularly challenging because they are uncommon, have a wide diversity in pathology and involve strict multi-disciplinary working between neurosurgeons, maxillofacial surgeons, ENT surgeons and clinical oncologists. They also need ITU back up, the surgery is particularly challenging and difficult and the prosthetics people are often involved because the surgery involves forming orbital exenteration and maxillectomy, etc.
British National Formulary (BNF)	Page 25	*'…Virus infections, including Herpes simplex…are associated with cancers of the oral cavity, pharynx etc..'* How are they associated? To what extent are they involved?	The text has been modified to amplify this point. Two systematic reviews have been carried out in Bristol, one of which has now been published and will be referenced. Both reviews implicate HPV in a clinically significant proportion of head and neck cancers, and this information has now been included.
British National Formulary (BNF)	Page 82	(4th line) Does the topical antibiotic paste or pastilles include antifungal agents, as these are often used.	The current draft goes into an inappropriate level of clinical detail and has been revised.
British National Formulary (BNF)	Page 82	Perhaps mention the use of oral fluconazole capsules for mucositis	See previous response.
British National Formulary (BNF)	Page 82	*'…patients should be educated about adverse effects of radiotherapy before treatment begins…'* What are the main ones? Are there any other likely effects of treatment e.g. nausea / vomiting / myelosuppression?	This is not dealt with in detail in the document because the potential complications depend on the site of radiotherapy. The areas of greatest concern are early complications such as mucositis, soreness and functional problems.
British National Formulary (BNF)	Page 87	(last line) Mitomycin C is a *brand* of mitomycin; suggest just calling it mitomycin.	Comment accepted. The text has been changed accordingly.

British National Formulary (BNF)	Page 88	Polymyxin E is known as colistin sulfate in the UK	No reference can be found to Polymyxin E in the current draft.
British Nuclear Medicine Society		It is firstly noted that this is guidance on commissioning and not clinical guidance. The development of PET and PETCT services in the management of head and neck cancers will become increasingly important at all stages of this disease and this should be indicated in the document to allow the correct development of future service.	Appropriate text has now been included to this effect.
British Nuclear Medicine Society		The MDT should ideally contain or have access to a nuclear medicine specialist with an interest in imaging of the head and neck. (The imaging with FDG PET or PETCT is new and complex with specific radiographic/technical expertise and a detailed knowledge of normal distributions of FDG in the head and neck required for correct interpretation.) The document at present implicitly implies a lack of nuclear medicine specialists in head and neck centres, and as PET and PETCT become increasingly important, there are training and resource implications for the provision of nuclear medicine services and specialists, which should be explicit. In thyroid cancer, the nuclear medicine specialist team is central to the imaging and radionuclide therapy of these patients. This again should be stressed, as at least a distinct advantage, even if such provision across the UK is difficult.	Agreed. The text has been amended. Specific reference is now made to a nuclear medicine specialist within the thyroid cancer MDT.
British Nuclear Medicine Society		PET has little role in the tumour staging of H&N cancer. This may not be true in PETCT but no published data is available. PET and PETCT do have a role in the detection of the unknown primary[1,2,3,4], especially as the lack of detection of the primary does affect outcomes. PET and PETCT will still miss some small UAT cancers detected by clinical examination and panendoscopy. A routine radionuclide thyroid scan for a dominant nodule in the thyroid is a simple and safe procedure which if a functioning nodule is demonstrated (15% of dominant nodules) no further investigations are required. In the initial investigation of thyroid	No comment required. No comment required. This view is not accepted. The British Thyroid Association Guidelines for the management of thyroid cancer in adults state that the essential pre-operative investigations are thyroid function tests, thyroid antibodies and FNAC with or without ultrasound scan guidance. They specifically make the point that isotope studies are usually non-diagnostic for the thyroid and are

		cancer, a technetium thyroid scan can reassure some patients about benignity if there is a functioning nodule.	best reserved for special circumstances in the pre-operative period and also for post-operative assessment and treatment. The guidelines offer evidence in support of that position.
British Nuclear Medicine Society		For initial regional nodal staging, PET is better than conventional clinical examination and imaging for the detection of nodal disease. In the two largest blinded, prospective studies (but single centred studies) PET was statistically significantly better than CT and MRI.[5,6] In the clinically N0 neck, PET and PETCT could also have a role in the future in allowing no neck dissection by improving the detection of macrometastases[7], but the lower sensitivity for the exclusion of micrometastases may preclude this.	This issue is covered in Topic 4.
British Nuclear Medicine Society		UAT cancer generally has a low prevalence of distant metastases and PET or PETCT is unlikely to identify distant disease in sufficient numbers of patients for this to be a reason for routine PET or PETCT. But these are both whole body techniques and distant disease will be assessed routinely if a PET is appropriate for other reasons. The detection of synchronous primaries in the UAT has been investigated with PET and can detect a significant number of synchronous primaries (25-11%) but the results are on small studies and conflicting results are also published.	The current description of PET (and by extension PETCT) is sufficient. There is not the evidence yet for a more detailed approach for head and neck cancers.
British Nuclear Medicine Society		See appropriate comments above.	See response to comment above.
British Nuclear Medicine Society		Treatment for thyroid cancer should include nuclear medicine as an <u>essential</u> and use of the phrase "….usually, nuclear medicine, is essential" is confusing and should be clarified. Either something is or is not essential and we would argue that the absolute desire of the thyroid MDT should be to include a nuclear medicine specialist. If this is not locally available then the commissioning document should indicate this as a requirement for a quality service. It should be noted that scientific support services and appropriate in-patient facilities are also essential for radionuclide	The quotation reflected back is in fact describing multidisciplinary management as 'essential'. The only reason for a conditional reference to nuclear medicine is that there are some places where other disciplines take on the role normally provided by nuclear medicine. If this is incorrect then we would welcome further comment.

		therapy of thyroid cancer. No established data is available at present to recommend or give advice on the use of PET or PETCT on response to radiotherapy, chemotherapy or chemoradiotherapy in UAT cancer. This is likely to be a rapidly developing area of further investigation. It is relevant to note that PET or PET CT is likely to have a role in the future in assisting radiotherapy planning. Research and service development should include the development of UK strategies for the investigation of PET and PETCT in head and neck cancer, probably one of the most important developments in the non-invasive imaging of epithelial cancers since CT.	The comments on PET are very pertinent. This is indeed an emerging technology and one which over the next two or three years is likely to be much more widely available to cancer teams in England and Wales than now. We are not seeking to anticipate future patterns of use, only to emphasise that there are already indications as to where a role is likely.
British Nuclear Medicine Society		PET should be available to detect recurrent disease and is the best non-invasive imaging modality especially in the presence of radiotherapy change. A number of studies have addressed this problem [8,9,10]. PET CT has a distinct advantage over PET allowing accurate localisation of the recurrent disease. The recurrent disease detected is often of small volume requiring repeated biopsy or close follow-up both clinically and with further PET. We would agree with the utility of PET and PETCT in the assessment of recurrent medullary thyroid cancer and in dedifferentiated non-iodine avid thyroid cancer in patients with a rising thyroglobulin. We would also point out that recognising the need for roll-out of PET facilities throughout the UK, a national framework for PET scanning is expected from the Department of Health during 2004.	The material in topics 7 and 9 has been divided, and topic 8 repositioned. Thus after Primary treatment - Topic 6 becomes 'Aftercare, rehabilitation and support' - Topic 7 becomes 'Follow-up and recurrent disease' - Topic 8 becomes 'Palliative Care' See response above about PET and PET CT.
British Nuclear Medicine Society		PET and PET CT are better than clinical assessment and conventional imaging (especially after radiotherapy) in the detection of recurrent disease.	Cross- reference has now been made to Recurrent Disease, where this is discussed.

		PET and PETCT have a role in the detection of new primary disease. If "salvage treatment can be curative when recurrence is identified early" then PET and PETCT will have a role in the identification of small volume recurrence with a possible benefit of surgery with more curative intent.	
British Nuclear Medicine Society	General	Positron emission tomography in UAT cancers PET, and especially PET CT, will have an increasing role to play in the management of these challenging diseases. This must be under the auspices of a MDT system with a dedicated nuclear medicine specialist team with an interest in head and neck cancer. Further research is undoubtedly needed to expand and establish the role of PET and PETCT and the UK should be at the forefront of that expansion.	 See response to point above. See response to point above. A new key recommendation makes the point about the urgent need for research into the effectiveness of management, including assessment.
British Nuclear Medicine Society	General	Thyroid cancer A nuclear medicine specialist team is <u>essential</u> for the provision of a high quality and safe imaging and therapeutic service. If the training and expansion of nuclear medicine specialists (clinical, scientific and technical) are impinging locally and nationally upon this requirement, then the guidance should say this. It is essential to recognise that the necessary infrastructure (shielded rooms, dedicated beds, supporting staff) must be present at all sites undertaking this type of therapy.	 Topic 2, Structure of services, has been substantially re-drafted. A nuclear medicine specialist is now included in the membership of the thyroid MDT, and in the extended head and neck cancer team. The following text has also been added in Topic 5, Primary Treatment: 'Further treatment…. is likely to require expertise and facilities which are only available in Cancer Centres. These include special rooms for patients undergoing radioiodine treatment, to prevent the spread of radioactivity into the wider environment.'
British Nuclear Medicine Society	References	1.Kole AC et al, Cancer 1998;82:1160-1166 2.Braams JW et al, Inter J Oral Maxillofacial Surg 1997;26:112-115 3.Aassar OS et al, Radiology 1999;210:177-181 4.Jungehulsing M et al, Head and Neck Surgery 2000;123:294-301	All the references used to support the guidance are included in the Research Evidence, available at the second consultation.

		5.Adams S et al, EJNM 1998;25:125-1260 6.Kau RJ et al, Head and Neck Surgery 1999;125:1322-1328 7.Myers LL et al, J Otolaryngol 1998;27:342-347 8.Farber LA et al,Laryngoscope1999;109:970-975 9.Koa CH et al, JCO 1998;16:3550-3555 10.Lowe VJ et al, JCO 2000;18:651-658	
British Oncology Pharmacy Association	Page 9	This document states 'it is *not* clinical guidance and does not include the level of detail that would be required to inform decision-making about specific treatments for individual patients', but later on page 82 gives specific guidance on mouthcare. The use of the word 'should' is too prescriptive and the wording should be adjusted to reflect the role and important of local treatment policies.	The detail on page 82 has now been removed.
British Oncology Pharmacy Association		This patient group often requires parenteral and/or enteral nutritional support and may have difficulty taking medicines orally or via PEG/NG tubes. Both issues require specialised pharmaceutical input at cancer centre and cancer unit/DGH level.	The following text has been added in the section on extended team members: 'Gastroenterologists, radiologists and GI surgeons for PEG or other enteral feeding tube placement and support.'
British Oncology Pharmacy Association		See above, which applies particularly to post-surgical patients and/or those undergoing R/T. (Structure of Services section 2) This patient group often requires parenteral and/or enteral nutritional support and may have difficulty taking medicines orally or via PEG/NG tubes. Both issues require specialised pharmaceutical input at cancer centre and cancer unit/DGH level.	This would be covered by the extended team members (see above).
British Oncology Pharmacy Association		The provision of chemotherapy to this patient group may increase in the Cancer Centres with more centralisation of services. This will have an impact on pharmacy services	Most chemotherapy used is likely to be given in the context of chemoradiation, i.e. already associated with radiotherapy centres. We are not making any specific recommendation to expand chemotherapy use as a single modality.
British Oncology Pharmacy Association		Specialised pharmaceutical input to design of treatment policies is essential.	This comment may well be correct but is not a point which need be made specifically in the guidance.
British Oncology Pharmacy Association		The Supportive and Palliative Care Guidance, to be published by NICE in early 2004, will provide generic recommendations. This will include have implications for pharmacy services in primary and secondary care	No response required.

British Psychological Society, The			This organisation was approached but did not respond.
British Psychosocial Oncology Society			This organisation was approached but did not respond.
British Society of Oral Medicine			This organisation was approached but did not respond.
BUPA			This organisation was approached but did not respond.
Cambridge Laboratories	Foreword	From a management point of view, oral mucositis, as a consequence of radiotherapy / chemotherapy affects a significant number of patients undergoing treatment for head and neck cancer. Any guidance examining service and management for these patients should emphasise the need to manage oral hygiene, in particular, the pain associated with oral mucositis as it significantly impacts on both the treatment course and quality of life of patients. The consequences of poor oral hygiene can impair the patient's ability to eat, drink and even speak.	The Foreword is Professor Haward's personal summary of some of the key issues – this kind of detail is inappropriate here.
Cambridge Laboratories	Key Recommendations	In bullet point 3, there is mention of services such as swallowing, nutrition and psychology. However, there is no mention of "oral hygiene and pain management i.e. due to oral mucositis". We recommend the insertion of this comment as this condition affects significant numbers of patients and impacts on the treatment regimen and their quality of life.	Too much detail for the Key recommendations.
Cambridge Laboratories	Page 9	For your information, we include background data on oral mucositis to emphasise the size of the issue, within oral hygiene management. The development of oral mucositis starts with a reddening of the mucosa (erythema)[grade 1]. This is followed by the appearance of smaller ulcers that may appear pseudomembraneous [grade 2]. These ulcers increase in size and join up to become confluent	This information is too detailed for the Background section.

		[grade 3], and in the most severe cases the mucosa will become necrotic and will spontaneously bleed [grade 4] [2]. Oral mucositis is induced by a range of oncology therapies. The cells of the oral mucosa have a rapid turnover time, which is why they are particularly vulnerable to cytotoxic therapies. The following information sections describe the presence and course of oral mucositis with various cancer treatment regimens.	
Cambridge Laboratories	Page 26	Radiotherapy to the head and neck Ionising radiation to the oral cavity for head and neck cancers is a common cause of damage to the oral mucosa. When the treatment field includes the oral mucosa, the patient will almost certainly experience oral mucositis[3]. Patients receiving concomitant chemotherapy are likely to progress to a more severe grade – as many as 88% of patients may experience grades 3 or 4 mucositis with particularly aggressive therapy[4]. Symptoms start 1-2 weeks after the first dose of radiation, and continue for 1-3 weeks after the last dose if there are no complicating factors. Patients with the most severe mucositis will often be given enteral nutrition. Head and neck cancer has an incidence of approximately 10 per 100,000 population[5]. Approximately 5,000 patients in England (out of a total population of 49,181,300[6]) each year will be diagnosed with head and neck cancer, of whom perhaps 90% will receive radiotherapy to the head and neck.	This information is too detailed for the Background section. A further comment has been added about patient support needs. Appropriate references are made in the ensuing sections.
Cambridge Laboratories	page 27	Recognises the need for service orientation to manage the side effects of radiotherapy, disabling patients and impacting on their quality of life. Oral hygiene strategies and management of pain	Too much detail for Background section.

[2] National Cancer Institute common toxicity criteria v2.0
[3] Sonis ST, Eilers JP, Epstein JB et al. Validation of a new scoring system for the assessment of clinical trial research of oral mucositis induced by radiation or chemotherapy. Cancer 1999; 85 (10): 2103-2113
[4] Lavertu P, Adelstein DJ, Saxton JP, et al. Aggressive Concurrent Chemoradiotherapy for Squamous Cell Head and Neck Cancer Arch Otolaryngol Head Neck Surg. 1999;125:142-148
[5] Cancer Research Campaign (1994)
[6] Office of National Statistics mid 2001 estimates

		are not mentioned and should be recognised for such cases, as this can adversely affect treatment and QoL.	
Cambridge Laboratories	page 28	Current service provision is highly variable and principally focused on cancer treatment, not necessarily on services during and post treatment.	There has been considerable amendment to the text referenced, which covers the point being made.
Cambridge Laboratories	page 32	Raises an important MDT member – clinical nurse specialist. These nurses are at the front end of managing these patients on a day-to-day basis and often recognise signs and symptoms before other members of the MDT. These individuals should have the authority to recommend simple medications and devices to manage oral hygiene and ease pain as agreed with the MDT.	The text on the role of the CNS has been revised, but there is a balance to strike between too much and too little detail for service guidance.
Cambridge Laboratories	Page 40	Although it is difficult to estimate the precise resource implication of managing oral mucositis, there are several studies that have highlighted the increased burden of care with this condition. a) dose-reduction Treatment delays and interruptions are likely to have a clinical impact on that patient's treatment plan. The NCI estimate that "a significant number of patients develop mucositis to such severity as to require modification in their overall medical management"[7]. A recent survey among UK Palliative Care professionals found that 57% employed dose reduction as a means of controlling the symptoms of oral mucositis[8]. *b) hospitalisation* One study showed an increase in hospitalisation days, in patients with standard-dose chemotherapy-induced mucositis[9]. Another study[10] found that in high-dose chemotherapy, a 1-point increase in grade of mucositis was associated with an additional 2.6 days in hospital. In these cases, hospitalisation may be a result of mucositis combined with other toxicities, but the need for adequate nutrition and hydration is a leading cause.	This is not an appropriate section for discussion of oral mucositis.

[7] National Cancer Institute Monograph 9, 1990
[8] Taylor Nelson Sofres market research, conducted January 2002 Data on File, Sinclair Pharmaceuticals – available on request.
[9] Manzullo et al. ASCO (American Society of Clinical Oncology) abstracts 1998; no. 1605
[10] Sonis ST, Oster G, Fuchs H, Bellm L et al. J Clin Oncol 2001; 19 (8): 2201-2205

		c) nutrition Patients whose mucositis prevents them from eating and drinking adequately may need to receive enteral, or even parenteral nutrition. Increasingly in the UK, head and neck radiotherapy patients are being fitted with prophylactic percutaneous gastrostomy tubes (PEGs) before radiotherapy is started. One recent study found that high-dose chemotherapy patients received on average 2.7 additional days of TPN (total parenteral nutrition)[10]. d) Additional medication and devices In addition to medications needed to address oral infections, the management of pain caused by oral mucositis is essential. A new device called the Gelclair is being increasingly employed to manage oral hygiene and the pain associated with oral mucositis.	
Cambridge Laboratories	page 44	We recognise the important roles of the pain management specialist, palliative care specialist and dietition with the extended MDT	No response required.
Cambridge Laboratories	page 46-48	From a patient perspective, the CNS is a key individual. This person needs to have the ability to make decisions regarding services required for patients under their care, during and after their cancer therapy.	Agreed.
Cambridge Laboratories	page 50	It is essential that data are passed onto GPs asap by the administrator and they should be briefed on the anticipated issues for oral hygiene such as pain from oral mucositis and how to manage it with simple devices such as the Gelclair.	Too specific for this section.
Cambridge Laboratories	Page 51	We recognise the value placed on the CNSs and we would like to emphasise the phrase “could reduce post-treatment hospital admissions by ensuring that problems are dealt with promptly and appropriately.” – this is highly relevant to pain associated with oral mucositis.	No response required.
Cambridge Laboratories	page 75	We recognise that patients should be informed of their treatments and consequences thereof, and ideally written information be provided to them.	No comment required.
Cambridge Laboratories	page 79	We recognise this paragraph which involves patients in their treatment and informs them of the consequences.	No response required.

Cambridge Laboratories	page 81	We wholly agree with the section regarding the avoidance of interruptions in the radiotherapy treatment regime. Oral Mucositis is a common cause of interruption/dose reduction. Treatment delays and interruptions are likely to have a clinical impact on that patients' treatment plan. The NCI estimate that "A significant number of patients develop mucositis to such severity as to require modification in their overall medical management"[5.] A recent survey among UK Palliative Care professionals found that 57% employed dose reduction as a means of controlling the symptoms of oral mucositis.[6]	This comment is very welcome as interruptions to treatment are detrimental to many patients. However, we have now included somewhat less detail about the mechanisms for treating mucositis while emphasising the importance of treating it.
Cambridge Laboratories	page 82	We agree with the recommendations on mouthcare and oral hygiene being emphasised to patients. However the recent Cochrane review[11] published in 2004, concluded that "There is weak and unreliable evidence that allopurinol mouthwash and vitamin E may be beneficial in curing mucositis." Management of pain is not mentioned in this section and should be recognised, the pain associated with Oral Mucositis can adversely affect treatment and Quality of Life.	The Cochrane review referred to was published after the searches were undertaken for the Research Evidence. Earlier Cochrane reviews looking at this area show that the evidence is unreliable. Pain control is included in the new Topic 8, Palliative interventions and care.
Cambridge Laboratories	page 82	We wholly agree with this section which highlights the importance of continuing the treatment course and having access to specialist services. Mention of the Gelclair device may raise awareness of a common problem of oral hygiene and managing the pain associated with oral mucositis.	This is an inappropriate level of detail; we have decided on a strategy of reducing the clinical detail about precise therapies for mucositis in favour of a more general requirement to address and manage the issue satisfactorily in the interests of patient welfare and the completion of treatment.
Cambridge Laboratories	page 88	Unfortunately there is no generally effective therapy for preventing oral mucositis. A recent Cochrane review[12] found that the strength of the evidence was variable and implications for practice include consideration that benefits may be specific for certain cancer types and treatment. A further Cochrane review[10] found that there was no generally effective treatment that achieved healing of oral mucositis, although certain mouthwashes and vitamin E may provide some	The issue of oral hygiene and oral mucositis is addressed in the manual – see above response for level of detail. This review was too recent to be included in the research evidence.

[11] Worthington HV, Clarkson JE, Eden OB. Interventions for treating oral mucositis for patients with cancer receiving treatment (Cochrane Review). From The Cochrane Library, Issue 1, 2004. Oxford
[12] Clarkson JE, Worthington HV, Eden OB. Interventions for preventing oral mucositis for patients with cancer receiving treatment (Cochrane review). From *The Cochrane Library, Issue 3, 2003*. Oxford

		benefit. Pain control will also affect the patients 'functionality', or ability to speak, eat and drink normally and therefore to maintain an adequate quality of life. It is often this lack of functionality that results in dose-reduction or hospitalisation, making pain and functionality control an even more important management objective for oral mucositis. The Gelclair is a device specifically indicated for use in the management of pain associated with oral mucositis caused by radio/chemo-therapy.	See response to point above. See response to point above.
Cambridge Laboratories	page 92	Point 3 should include access to devices to manage the pain associated with oral mucositis.	Mucositis is included in the process where it describes the use of prophylactic measures to prevent mucositis. This includes all forms of intervention.
Cambridge Laboratories	page 104	We recognise the statement on page 105 with respect to educating patients and their carers about "mouth and dental care" and that they should know who to contact if problems arise such as pain associated with oral mucositis.	No response required.
Cambridge Laboratories	page 105	Could mention oral hygiene and mucositis pain management as an example.	These are aims – examples not required.
Cambridge Laboratories	page 106	Emphasis on the follow-up post radiotherapy adverse events are treatable such as pain associated with oral mucositis.	This point is adequately covered.
Cambridge Laboratories	General	With no generally effective therapy currently available for prevention or control of clinical signs (inflammation and ulceration) it is important to focus on the control of the symptoms (pain and functionality). Oral lesions cause pain because the exposed nerve endings, or those surrounded by inflammation, are over stimulated. Mechanical or chemical stimuli within the mouth such as that caused by eating, drinking or speaking, stimulate these receptors further and can be extremely painful.	See responses to points above.

		The Gelclair has been shown to provide good pain relief and improved functionality (eating, drinking, etc) for oral mucositis in four symptom-response studies.[13,14,15,16] The Gelclair is presented as a concentrated oral gel for managing the painful symptoms of oral mucositis. It contains the barrier-forming ingredients PVP (polyvinylpyrrolidone) and sodium hyaluronate. When Gelclair is used as an oral solution, these ingredients adhere to the mucosa to form a protective barrier. The physical barrier over the surface of the oral mucosa that is formed by the Gelclair shields receptors from over stimulation. In this way the Gelclair can reduce the pain of oral mucositis and can also enable patients to eat and drink more easily while they have the condition. The Gelclair is a Class I Medical Device (due to its mode of action) it is not pharmacologically active and as such has no known interactions.17	
Cancer Research UK			This organisation was approached but did not respond.
Cancer Services Co-ordinating Group		Please see joint response under Welsh Assembly Government	Thank you.
Cancer Voices			This organisation was approached but did not respond.
CancerBACUP			This organisation was approached but did not respond.
Cephalon UK			This organisation was approached but did not respond.

[13] Innocenti et al. Efficacy of Gelclair in reducing pain in palliative care patients with oral lesions: preliminary findings from an open pilot study. J Pain Symptom Manage. Nov 2002; 24 (5): 456-7

[14] De Cordi et al. Gelclair: potentially an efficacious treatment for chemotherapy-induced mucositis. Abstract: Italian Tumour League III congress for professional oncology nurses, Conegliano, Italy, 10-12 October 2001.

[15] Berndtson M, A Preliminary Study of Orassist (Gelclair) in the management of Oral Mucositis. Svensk Sjukhustandlakartidning (Swedish Hospital Dentistry) 2001 Nr 3 (Argang 26) pp17-21.

[16] Bonassi et al.Treatment with Gelclair in patients suffering grade III-IV oral mucositis: efficacy and impact on quality of life (QOL). Abstract : Ann Oncol, 2003; 14(4) Suppl E38

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Ltd			
Changing Faces	p. 62	Recommend patients are accompanied by a relative or friend so all questions are asked and to discuss consultation with someone afterwards	This point is now reflected in the text. Sentence added: 'Patients should be encouraged to bring a carer or relative to the appointment at which they are to be told that they have cancer.'
Changing Faces		Encourage patients to make a list of questions prior to appointments, and to take pen and paper to make notes	This point is now reflected in the text. Sentence added: 'Patients should be advised to make lists of their questions prior to appointments, and to take pen and paper so that they can make notes.'
Changing Faces		Request extra time for appointments if they need to discuss concerns more fully	This point is now reflected in the text. Sentence added: 'Patients should be advised to make lists of their questions prior to appointments, and to take pen and paper so that they can make notes.'
Changing Faces		See 'Talking to Health Professionals' by *Changing Faces*	The points made are now reflected in the text.
Changing Faces	p. 65	Vital to consider in pre-treatment, early days post-op, and long-term rehabilitation	No response required.
Changing Faces	p. 76	*See* Dropkin, M. J. (2001) Anxiety, Coping Strategies and Coping Behaviours in Patients undergoing Head and Neck Surgery. *Cancer Nursing*, 24 (2), 143-148.	This reference was assessed as part of the evidence review.
Changing Faces		Preparation for Discharge: Patients with disfigurements should have something to say in response to others' reactions	Not clear exactly what this relates to. There is already a paragraph about the problems of disfigurement.
Changing Faces		See Clarke, A. (1998) 'What Happened to your Face?' Strategies for Managing Facial Disfigurement. *British Journal of Community Nursing*, 3, (1), 13-16	No response required.
Changing Faces	General	See 'When Cancer Affects the Way You Look' by *Changing Faces*	No response required.
Changing Faces		See Clarke, A & Cooper, C (2000). Psychosocial rehabilitation after disfiguring injury or disease: investigating the training needs of specialist nurses. *Journal of Advanced Nursing, 33 (6), 1-9*	No response required.
Chartered Society of Physiotherapy	General	We welcome this document and appreciate the hard work that been undertaken in developing it. We also welcome the cross referencing to the NICE supportive and palliative care document (in press)	Thank you.

Chartered Society of Physiotherapy	Page 8	This list could also include '*respiratory* and *facial rehabilitation'* services.	The wording of the key recommendations has been substantially revised.
Chartered Society of Physiotherapy	Page 27	We welcome this section. We are pleased to see recognition of the 'range of clinicians involved in its care and treatment'. We would wish to see expansion of this discussion. This could include a greater appreciation of the problems that arise, such as fibrosis and loss of range of movement/function of the neck and shoulder, and a subsequent wider range of clinicians (including the other allied health professions), who are involved in care of these 'many side effects' of radiotherapy and surgery. The second paragraph in this section recognises the problems of breathing, excess secretions and facial disfigurement; all problems that require respiratory services and facial rehabilitation, and the appropriately trained professionals to assist the patient manage.	No response required. Too much detail for the Background section.
Chartered Society of Physiotherapy	Page 43	We are surprised to see physiotherapists omitted from the core team, and only included in the extended team. Our expectation is that many patients included in the scope of this guidance would need to see a physiotherapist at some stage of the care journey. This would be pre-operatively and post-operatively and following radiotherapy and chemotherapy.	It is not expected that they would be required to attend every meeting, but only those where their expertise is required.
Chartered Society of Physiotherapy	Page 45	We are surprised not to see Lymphoedema specialists as part of this extended team.	We would expect other team members (whether core or extended) to call on this expertise as required.
Chartered Society of Physiotherapy	page 105	We welcome this section and the recognition of the role physiotherapists have to offer. We are surprised that more detail isn't given, in a similar fashion to that of the speech and language therapists (page 106), outlining the role for the physiotherapists and occupational	More text has now been added.

		therapists. This would help commissioners see the value of their role; in what might otherwise be misunderstood.	
CHI	3(b)	Now that Cancer Networks are often the means through which delivery is achieved it would seem appropriate to include a reference to them here	It is not possible to respond to these 4 points as the page references are unclear – please clarify.
CHI	3(b)	It might be more helpful to refer to Strategic Health Authorities	It is not possible to respond to these 4 points as the page references are unclear – please clarify.
CHI	3(b)	Should Foundation Trusts and/or independent health care providers be referred to?	It is not possible to respond to these 4 points as the page references are unclear – please clarify.
CHI	4.6	Include a reference to the needs of specific patient or population specific groups such as those of particular ethnic origin or defined by particular socio-economic characteristics.	It is not possible to respond to these 4 points as the page references are unclear – please clarify.
College of Occupational Therapists	General	The College of Occupational Therapists has no comments to make on this draft.	This organisation responded and said that it has no comments to make.
Department of Health	General	The report emphases the role of Clinical Nurse Specialist at Multidisciplinary Team and local level. This is likely to lead to widening of this role, possibly at the expense of Speech and Language Therapists and other Allied Health Professionals. The report states that the CNS is the professional skilled in picking up all the psychological and social issues that doctors would not. However this is a role that AHPs and SALTs have also been doing for many years This is recognised on p67 where SALTs are cited alongside CNS for being appreciated for clear info giving and support. This is an apparent contradiction. Could you consider please?	The balance has now been changed in the text, with additional information on roles other than that of the CNS now included. The text on the role of the CNS has also been revised.
Department of Health	pg 8	Would you consider explaining in more detail what the MDTs would look like? In our view it is likely that resources would need to be given to local SALT departments to allow for the diversity of skills that may be called upon - for example, following up PEG patients after oral surgery versus the rehab needs of laryngectomees. The head and neck MDT may not be aware of the diversity of skills a SALT needs. At a local level the appropriate SALT will depend on the patient's specific disorder as needs could be very different. Would you consider the possible resource implications?	Topic 2, Structure of services, including the roles and membership of the MDTs, has been substantially revised. The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation.

Department of Health	Page 13	Could you please check the figure of 40% in the increase of oral cancers between 1997 and 2000? In our view it seems to be rather high.	The sentence containing this figure has now been deleted.
Department of Health	Page 22	Could you please check the figure of 1350 for *'other types of cancer'* as it is not clear whether it reconciles with table 1a (p.10)?	This figure has now been deleted.
Department of Health	Page 26	Would you consider replacing '(*particularly if patients are treated with radiotherapy*)' with '(*particularly for patients not undergoing surgery)'?*	Agreed. Amendment made.
Department of Health	Page 41	Could we ask that you highlight here (or elsewhere) the importance of clinical audit, especially the Data for Head and Neck Oncology (DAHNO) project which forms part of the National Clinical Audit Support Programme?	Appropriate references have now been made.
Department of Health	Page 44	Would you consider adding a further bullet: '*anaesthetists'*? This would correspond directly to the recommendation given on p.71, *'Anaesthetic Assessment'*?	Agreed. Now included.
Department of Health	Page 48	Would you consider rewording the second sentence of this section so that it reads as follows: '*The SALT can assist in answering patients questions about the impact of proposed treatments on their speaking and swallowing, and inform team decision making. The SALT will liaise with colleagues where treatment is planned offsite. Treatment plans will be discussed at an appropriate time before treatment commences*'.	The wording now reads as follows: 'The SLT should share responsibility with other MDT members for assessment of communication and swallowing before treatment, discussing the potential impact of proposed treatments on speaking and swallowing with the patient, and should contribute to MDT discussion on treatment planning. During and after treatment, the SLT's role includes helping patients to overcome problems with eating, drinking and communication. Therapy to help people to swallow and communicate effectively after radical treatment demands a high level of expertise, and a dedicated SLT should be available to work on rehabilitation with such patients for substantial periods of time'.
Department of Health		Whilst it is likely to be desirable to have a SALT present at the MDT meeting, this may not be possible because of the number of SALT sessions allocated to head and neck work in the week. Could you please consider this further in the next draft?	The recommendation describes what should happen. The issue of SLTs is addressed in the economic review, available with the second draft.
Department of Health	Page 48	Could we ask that '*community dental services*' be replaced with '*primary care dental services*'?	Amendment made.
Department of	Page 48	Would you consider rewording this section to:	This sentence is already included in the relevant section

Health		*'Patients who are dependent on tobacco, alcohol, or other addictive substances associated with increased risk of head and neck cancer, should be offered interventions and support to help them quit*'?	on pre-treatment, assessment and management. The sentence referred to here is about the need for psychological services, rather than the nature of the services to be offered.
Department of Health	Page 71	Could you consider replacing the words " *to restore speech"* with 'on *restoring communicative and swallowing function'* as in our view it gives a misleading description of the role of the SALT? Whilst restoration is appropriate when talking about surgical voice restoration, SALTs also have a role in maximising speech and swallowing function through therapy and the teaching of compensatory strategies.	This comment is accepted and has been made by others. The text has been revised accordingly. The current draft now reads as follows: 'The SLT…will work with the patient to make the most of his or her potential for recovery of speech, voice and swallowing.'
Department of Health	Page 78	Would you consider redrafting as follows: '*Evidence that patients who are dependent on alcohol, nicotine or other drugs receive <u>a care plan addressing their requirements for counselling</u> and/or cognitive-behaviour therapy to help them to quit before definitive treatment begins'?* In our view it seems arbitrary to withhold definitive treatment for cancer on the basis of receipt of a therapy, for which there may be waiting lists or which may require time for motivational changes in the individual to engage in the treatment of addiction. In our opinion success rates of cancer treatment and risk/benefit analysis are different processes. Would you agree that this should be made clear if what is proposed is necessary for monitoring?	The point is accepted and the text for this paragraph will be revisited as part of our review of the Measurement section. Whilst it is important that patients are offered access to services which may help them with underlying problems of dependency or addiction, these are not the dominant issues in treating their cancer. It is not the intention of the document to imply that patients' access to cancer treatment would be seriously delayed by attending to long-standing problems of dependency or addiction.
Department of Health	Page 100	In addition to the management of airway obstruction it would be helpful if you could indicate the importance of management of acute haemorrhage in palliative care, together with an expedited pathway for admission to the specialist head and neck oncology ward. Would you please consider this?	The requirement to deal with acute haemorrhage in palliative care is already dealt with. An admission pathway is not required.
Department of Health	Pages 100 - 101	This recommendation causes us some concern because in our view: • A patient in any kind of respiratory distress should ideally go to A&E resuscitation, with the ambulance service forewarning for such an emergency. Any such patients would therefore be managed as a resuscitation call.	The intention is for appropriate patients to be able to go straight to the ward. Patients in the example quoted would go to A&E. The wording has been revised from 'patients with acute airway obstruction are admitted' to

		• If resuscitation is needed then A&E is the most likely place in the hospital to provide immediate intensive care treatment and has an anaesthetist on site. • A&E regularly call upon the services of other appropriate specialist teams who then come to the A&E department. • In an emergency patients are more likely to see a senior doctor in A&E than on an ENT ward. • We understand that most ENT services have junior medical cover on their wards out of hours. In this instance a comprehensive hand-over from ambulance staff may present difficulties.	'patients with anticipated acute airway obstruction can be admitted.' This point was extensively discussed by the Editorial Board, and this was not their view.' The nature of the ward is defined – not just an 'ENT ward'. See above.
Department of Health	Page 101	We have identified several points that we think might benefit from clarification: • Could you explain whether this point implies a training requirement for ambulance staff to better deal with tracheostomies? • We agree that specific training should be provided for staff whom are likely to deal with these patients, but could you clarify whether this includes A&E staff? • Also could you explain if A&E staff would be able to call on services of specialist staff in an ENT ward?	Training emergency staff in the management of emergency conditions is a generic issue. The aim of the recommendation is to ensure that wherever possible, patients should be admitted direct to the specialist care of trained staff on the appropriate ward. The emphasis is not on A&E (see above).
Department of Health	Page 101	We support the recommendation that a patient with a non-life threatening condition or who requires palliative care in hospital can be admitted directly to the head & neck unit, by an ambulance service or primary care. However, could you explain whether this process would need to be reflected in a locally agreed operational procedure between the hospital and the ambulance service? We agree that the key point in this section is patient choice in where they receive care. The terminal phase in head and neck cancer can be very distressing for the patient and relatives and could result in the patient being rushed to hospital via A&E. Would you consider highlighting that perhaps the ambulance service should have access to palliative care services to help with	The arrangements to re-admit to wards not via A&E are essentially operational issues for the Trusts involved within each network (and therefore reflecting a network view on clinical policy). Ambulance services need to be aware of the local policy but it does not have much effect on what they do in practice. This is a bridge too far for site-specific guidance for head and neck cancers. The position of ambulance services in difficult or distressing terminal care is a generic issue, which should be covered by the recently-published guidance for 'Improving Supportive and Palliative Care

		terminal illness emergencies and to ensure that patients can continue to be managed at home if that is their wish?	for Adults with Cancer'.
Department of Health	Page 105	Would you consider whether there is a role for the specialist nurse practitioner here in the management of surgical wounds, flaps and donor sites especially in the event of wound breakdown, fistulae and delayed healing'.	These are not clinical guidelines. This would be determined locally.
Department of Health	Page 109	In our view the quoted American study is perhaps not a good comparator to current UK practice. The majority of British laryngectomies offered are surgical restoration and the numbers relying on oesophageal speech therapy is low. Would you consider further please?	This is the only available evidence, and its role is clear in the text (see first para).
Eisai Limited			This organisation was approached but did not respond.
Eli Lilly and Company Ltd			This organisation was approached but did not respond.
Faculty of Dental Surgery			This organisation was approached but did not respond.
Faculty of Public Health			This organisation was approached but did not respond.
General Medical Council			This organisation was approached but did not respond.
Help Adolescents with Cancer			This organisation was approached but did not respond.
Help the Hospices			This organisation was approached but did not respond.
Institute of Physics and Engineering in Medicine			This organisation was approached but did not respond.
Intensive Care Society			This organisation was approached but did not respond.
Isle of Wight NHS Trust			This organisation was approached but did not respond.
Joint Committee on Palliative Medicine			This organisation was approached but did not respond.

Let's Face it			This organisation was approached but did not respond.
Link Pharmaceuticals			This organisation was approached but did not respond.
Macmillan Cancer Relief	General	Overall this is a well-written document which will provide guidance for the future. We feel the key recommendations are very appropriate.	Thank you. No response required.
Macmillan Cancer Relief	General	The use of the word dietitian is inconsistently spelt, and we would prefer the spelling 'dietitian'.	The spelling is now consistent throughout.
Macmillan Cancer Relief	Foreword	This was very well written and set out the agenda for the document well.	Thank you.
Macmillan Cancer Relief	Key recommendations	We suggest the use of the term dietetics rather than nutrition.	The key recommendation referred to has now been re-written.
Macmillan Cancer Relief	Key recommendations	Clarification is required on what is meant by supporting data collection services. Money and time are required if specialist services are going to undertake research. Data collection should also encompass treatment and rehabilitation, as this information may influence patient's treatment decisions in the future (for example to weigh up survival against quality of life).	The wording of the key recommendations has been substantially revised. A recommendation is now also included about the importance and urgency of research into the effectiveness of management.
Macmillan Cancer Relief	Page 30,	We are unclear as to whether this means a lead clinician for both ENT and maxillofacial combined or a lead consultant in each speciality. If it refers to the lead clinician for head and neck cancer services then this may not be appropriate, as where there are both ENT and maxillofacial consultants they would see these patients personally.	This text has now been revised, to clarify. The term 'lead clinician' has been changed to 'designated' clinician, and the text further re-worded.
Macmillan Cancer Relief		We would make the following points with regard to the referral guidelines: • Pain: Sometimes the patient can present with referred earache (or odynophagia) unaware of a lesion in the oro-pharynx or persistent sore throat • Loss of sensation: can be implicated in parotid carcinoma • Stridor: is implicated in thyroid cancer but should also be implicated in the urgent referral in cases of laryngeal or pharyngeal cancer • Persistent cough/irritation	The urgent referral criteria are taken verbatim from the DH criteria. These are currently being revised by NICE.

		• Audiological symptoms: tinnitus/otalgia/deafness • Neurological symtoms instead of cranial neuropathies (headache, cranial nerve palsies, diplopia) • Horners syndrome can be a clinical feature of nasopharyngeal carcinoma • Unilateral nasal obstruction or discharge/epistaxis • Trismus • Bleeding or contact bleeding	
Macmillan Cancer Relief	page 41	We agree that all patients with head and neck cancer should be managed via a multidisciplinary team (MDT) and agree with the guidance recommendations for MDT membership and responsibilities.	No response required.
Macmillan Cancer Relief		We regard the role of the dietitian as essential and would welcome further detail of this role and recognition on the importance and effectiveness of dietetics in this section. The physiotherapist with a specialist interest in head and neck cancer should be mentioned here. Their input is essential because many patients have underlying chronic chest problems (usually associated with smoking) and one of the continued rehabilitation problems is shoulder dysfunction (previous audit has shown it to be the most common symptom (before dry mouth) over two years after treatment). A dental hygienist or nurse is essential for most if not all patients.	A paragraph describing the role of the dietitian has been added. Physiotherapist and dental hygienist are in the extended team.
Macmillan Cancer Relief	page 46	We believe that all patients should have access to a CNS, as necessary. There may be some patients who do not wish to see the CNS initially though this may change throughout the pathway. Effective administrative support for MDTs is essential and should not be the responsibility of the CNS. CNS intervention may be through supporting other MDT members. Direct intervention from a CNS may not always be necessary. Contact details should be provided as already stated from	Agreed. Agreed, and already covered in the text. Already covered in the text.

		diagnosis. Copies of correspondence with GPs of all new diagnoses should go to CNS. The time before the treatment decision is made at the MDT can be essential for assessing the patient's psycho-social status, alcohol and smoking history and patients knowledge and understanding. Much can be achieved during this time and the CNS can also have input at the MDT about the patient's circumstances. Treatment decisions are often more complex and this is often an important role for the CNS, who can work flexibly and across sectors and with the patient's or carer's particular needs in mind. There remains an issue of specialist services being involved with head and neck patients, not just for the initial assessment but long-term. Specialist services should not only be available but also resourced properly. There is no mention of physiotherapy here: it should be provided with other services (many patients have chronic chests and may have to give up work or other activity due to shoulder dysfunction). Not all CNSs have direct responsibility for managing patients with tracheostomies, gastrostomies, prostheses and difficult wounds. However, where this is the case, the CNS should be able to signpost to the most appropriate professional.	This point is covered in new text, although may not contain every detail. Agreed. Resource issues are covered within the economic review. The physiotherapist a member of the extended team. Agreed.
Macmillan Cancer Relief		Assessment of patients' needs for psychological support and provision of services will be essential. Staff too may benefit from education in this area.	Included in the pre-treatment section.
Macmillan Cancer Relief	page 58	This will be difficult to evidence as not all patients need or wish to be interviewed by the CNS. It would be preferable to suggest that all patients are offered access to the CNS and given their contact details.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that all patients are assessed by a CNS.
Macmillan Cancer Relief	page 59	We suggest that the cost and resource needs of a dietitian specialising in head and neck cancer are included.	A generic statement has been added to the resource implications.
Macmillan Cancer Relief	Page 62	We support the proposal that all patients should have contact details for the CNS and opportunities for access. Where there are MDT members with specific enhanced skills, CNS involvement in every consultation may not be necessary.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that all patients are seen assessed by a CNS. The guidance now specifically mentions these

		All staff seeing patients at diagnosis should receive training and follow 'Breaking Bad News' guidelines.	guidelines: see text below. 'All members of the head and neck cancer MDT, and particularly senior clinicians who may break the news to patients that they have cancer, should have training in communication skills and should follow the 'Breaking Bad News' guidelines.'
Macmillan Cancer Relief		Written information: As part of NCA, a patient-held file 'teamwork project' was evaluated in 2001. Recommendations centre around MDT agreement on information given to patients, points in pathway in which information is given, training focussing on information needs/preferences and information delivery.	No response required.
Macmillan Cancer Relief		Other stages in the pre-treatment assessment and management should include: • Physiotherapy: shoulder function pre-op and chest • Dental assessment should include restorative dentist for patients considering maxillectomy • Psycho-social assessment is imperative. The CNS can be instrumental in informing the community team. Sometimes an 'outreach' visit is very constructive and any social needs can be addressed and considered which will often reduce delays in discharge or smoother functioning/communication across sectors. • In the case of difficult symptom control referral should be made to the Palliative Care specialist team. • Care manager: advice from social services can be invaluable specifically at this time for patients who have financial difficulty, are self employed or have social problems or are limited in any way and need carer support in the home. • Occupational therapy for patients requiring equipment or assessment of need.	These comments all concern access to specific expertise which many or all patients are likely to require. Some of these personnel are listed as core team members, such as restorative dentist or palliative care, others as Extended Team members, e.g. physiotherapist and dental hygienist. The roles of each of these disciplines are described under Topic 2 which is when these issues are addressed. We have not described the roles of each discipline in the work-up of patients in the pre-treatment phase. The presumption is that the MDT, when discussing these patients, will identify what is required in particular cases. What the section in the document is highlighting are the main areas of assessment activity. We hope that the combination of the short sections under Topic 4 and the specification of team members in Topic 2 will deal with the points raised in this comment.
Macmillan Cancer Relief	Section 4	A dietitian should see the patient at pre-treatment assessment due to the major implications of the treatment. This will also have a resource implication.	Our recommendations do identify that dietitians need to make assessments of these patients. This matter has been picked up in the Resource Implications since it is clear that the extended support needed by many head and neck cancer patients is one of the main areas for improvement in quality of life outcomes.
Macmillan	Section	The nutritional assessment studies are not referenced. We would	All studies used in the evidence review are fully

Cancer Relief	4	like to highlight research undertaken by Julie Lees at Clatterbridge on patients having radiotherapy (Nasogastric and percutaneous endoscopic gastrostomy feeding for head and neck cancer patients receiving radiotherapy treatment at a regional oncology unit, *Eur J Cancer Care 1997 Mar; 6(1):45-9* and Incidence of weight loss in head and neck cancer patients on commencing radiotherapy treatment at a regional oncology centre, *Eur J Cancer Care 1999 Sep; 8(3):133-6*).	referenced in the evidence review document, available at the second consultation phase.
Macmillan Cancer Relief	Section 4	We suggest that this section states the resource implications of having a dietary assessment, or state the cost of dietetic audit/ research. There should also be agreed sessions for physiotherapy, dental hygiene and psycho-oncology time.	The economic analysis of the cost impact of the main recommendations in the guidance, to be available at the next consultation stage, makes assumptions about the additional staff numbers and time necessary to implement the guidance.
Macmillan Cancer Relief	Section 5	With regard to the data collected throughout a patient's cancer journey to monitor the quality of service and treatment outcomes, we suggest that specific reference should be made to the national data for head and neck cancer (DAHNO) project being undertaken by the National Clinical Audit Support Programme, which is aiming to collect such data on patients with oral and laryngeal cancer (website: http://www.dahno.com). We also suggest that a higher profile be given to assessing quality of life after treatment for head and neck cancer. Once a treatment decision is made which will affect swallowing, there needs to be consultation between the consultant, dietitian, CNS and SALT to discuss enteral feeding. The Primary Health Care Team should be made aware of these decision so that preparation can be made at home, and education given to patients and relatives. There is no section on complications. These may be immediately post-operative but also long-term. Complications requiring in-patient stay should be discussed by the MDT.	The first point about information collection is of importance and is topical in view of the range of initiatives involving head and neck cancer, currently under development. We have captured this in a new Key Recommendation for the document which gives it much greater prominence. The second point has already been dealt with in the previous Topic 4.
Macmillan Cancer Relief	Section 5	We think this section needs more and better references to the studies mentioned.	The references to studies of various kinds, research and audit, within the narrative in the manual are intended to give a flavour of the evidence. It is not a substitute for

			the full Evidence Review which lists the results of systematic evidence reviews against pre-set questions. The draft Evidence Review will be available in the next round of consultation.
Macmillan Cancer Relief	Section 5	The resource implications should state the costs of the dietitian.	Staffing implications of the guidance in broad terms are being examined through the cost impact study done by the Health Economic Groups at ScHARR. This information will be available in the next phase of consultation.
Macmillan Cancer Relief	Section 8	This is an excellent section overall. The concept of local support teams will benefit the patient and carers by meeting the long-term needs. We recommend the use of an effective screening tool for the assessment of long-term problems (eg Quality of Life). Patients coming back after radical radiotherapy often have poor mobility of their shoulder and there should be an agreed strategy for dealing with shoulder dysfunction, for which patients often require ongoing physiotherapy. More could be made of the importance of ongoing liaison with the PHCT, which can make a difference to patient outcome and choices about their care. Benefits advice or social services information should be made available to patients: cancer and its treatment can often impose a huge financial burden on the patient. This should be recognised and information provided for the patient before and after treatment.	Already included. Reference to physiotherapy has now been included. Benefits advice is a generic issue, not specific to this group of patients.
Macmillan Cancer Relief	Section 8	There is recognition of the importance of community or hospital follow-up of head and neck patients but this will have cost implications which need to be recognised.	This is already included in the general statement. The Economic Review will highlight specific problems.
Medicines and Healthcare Products Regulatory Agency (MHRA)			This organisation was approached but did not respond.

Merck Pharmaceuticals			This organisation was approached but did not respond.
National Association of Laryngectomee Clubs			This organisation was approached but did not respond.
National Association of Laryngectomee Clubs (NALC)	Forward	2nd paragraph last sentence Most need rehabilitation……..the best care, most people experience……..access to services.	This is Professor Haward's personal summary. Proposed amendment not accepted.
NALC		3rd paragraph could be used by commentators to undermine treatment and to reduce access to research – recognise it may be PC but should be revised to achieve best practice and additional funding, already the smoking reduction programmes are discriminatory – aimed at manual workers.	Again, this is a personal summary of some of the issues, and this interpretation is not accepted. A key recommendation has now been added about the urgency of research into the effectiveness of management of these cancers.
NALC		Reference could/should be made to first line on page 25	All the references used to support the guidance are included in the Research Evidence, available at the second consultation.
NALC	Page 5	Recognise the positive value of locally based services however their will clearly be a need for additional skills training which will need to be funded. This is a priority for patients in rural areas but should not deny the patient access to the tertiary centre, if that is felt appropriate.	The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation.
NALC	Page 13	Deprived areas – no mention of occupational risk, many deprived areas have large numbers of residents from nearby heavy industry/transport occupations.	Occupational exposure is mentioned. We have not seen any research evidence which specifically links heavy industry/ transport with head and neck cancers. Please supply details.
NALC	Page 18	Table 3 descriptor is too negative some positive comment required, - would many patients already be debilitated if earlier referral became the 'norm'	The text around table 3 has been re-worded, although the developer is unclear about the specific point being made.
NALC	Page 20	2nd para fails to address the potential impact that access to 'free' dental checks up could bring.	This issue is outside the scope of the document.
NALC	Page 21	No mention of need to produce preventive information targeted in the southern Asian/Chinese ethnic group languages.	New text has now been inserted to cover this.
NALC	Page 25	Would welcome further research into genetic disposition particularly the Viking gene link.	Too much detail for the Background section.

		And Iodine deficiency Programme of awareness raising with Primary Care practitioners should include genetic, occupational and virus risks. Those practicing in areas with iodine deficiency should receive initial information ASAP.	
NALC	Page 26	should address the implications of dental check up costs and access to dental care and the cost of lack of provision - recommendation return to free dental check ups – as screening protocol. Recognition of the damage to teeth and bones of the head & neck area resulting from radiotherapy, on prognosis of ongoing difficulties, following surgery and future dentistry should be addressed. PCTs do not appear to recognise the later as part of continuing care of these patients.	Free dental check-ups are beyond the scope of this guidance. This is addressed in later parts of the manual.
NALC	Page 27	1st para last line amend to read –continued access to specialised dentistry <u>are</u> also needed + Some recognition of Carers in the partnership of care – aim to improve outcomes	Agreed. Text amended. The role of the carer is described in the main body of the manual; reference to carers has now also been made within the Background section.
NALC	Referral - Page 30	Clear protocols needed including the requirement to use FAX to ensure 24 hour time limit to referral – in all cases where cancer is suspected particularly from district clinician onward referral – some evidence that this is where many delays occur. [Suggest that protocols requiring FAX rather than letters for ALL referrals}	Relates to urgent referral guidelines, which are referenced in the manual.
NALC	page 31	Reference to referral letter in page 31 amend to faxed referral form, which can improve access for those with special needs	Relates to urgent referral guidelines, which are referenced in the manual.
NALC	Page 32	Concerned that there is lack of highlighting, to patients and primary care practitioners that Non Smokers MUST be referred, not reassurance that patients are too young, don't drink or smoke	The text does not imply this; the referral of these patients is not precluded.
NALC	Page 34	3rd para forms sent should be amended to forms faxed	Subject to local protocol.
NALC	Page 36	4th para should be recognition that routine dental inspection is not available for many patients.	This is outside the brief of this guidance.
NALC	Page 37	first paragraph is confused.	Please clarify what is meant by this remark.
NALC	Page 38	These delays should be highlighted as the main areas which if addressed would ensure 'quick hit' improvement.	This is a summary of evidence, not recommendations.
NALC	Page 39	2nd last para ALL units should have FAX communication well	Subject to local protocol.

		advertised to ALL Primary Care practitioners. Failure to use this method should be recorded by SHA.	
NALC	Page 40	Audit of delays should be added to monthly reported stats for star rating to ensure compliance, and improvement in outcome Outcome 1st bullet point confusing.	Outside the remit of this guidance. This has now been deleted.
NALC	Page 42	final sentence – access to teleconferencing should be a priority in widespread networks.	No response required; this point is already covered.
NALC	Page 45	Specialist Benefits Advisor – is required by this vulnerable group of patients frequently denied benefits despite contact with Benefits Agency Advisory Board.	Included in extended team.
NALC	Page 47	CNS needs skills to assess level of any current disability, especially where that already reduces communication by the patient. 3rd para education role to include neck breather training, in airway management and resuscitation. In addition awareness if feeding problems should be included in disability awareness training.	All these issues are already covered in the manual. The section on the CNS has been re-written.
NALC	Page 48	benefits advisor must have specific skill in communication disability awareness The recommendations for SALT and dental services must be absolute recommendations for the final report.	This is already covered in the introductory paragraph to the extend team members list.
NALC	Page 55	There is recognition by commissioners that the transfer of resources issue needs to be resolved not only to reduce waiting times but also provide access for host community.	No response required.
NALC	Page 57	1st para last line patients must have access to services of hospital dental clinic or appropriate high skill alternative provision.	This is the Evidence section (not a recommendation).
NALC	Page 59	There appears to be a lack of recognition appropriate work load and the need for a resulting increased status for CNSs – need to be 'friend' of patient not part of the 'them' But of the 'us' CNS's networks should ensure that they are not required to wear hospital uniforms when undertaking this role.	Workload requirements will be covered in the Economic Review. Not appropriate for this guidance.
NALC	Page 61	it is essential that information is available in ALL appropriate formats and languages – where 'written' is in text this protocol should be indicated.	This is covered in the 4th para of the section on informing patients.
NALC	Page 62	paragraph 4 Those who give this information…….preconceptions, needs and reactions;	'Needs' is not a valid alternative to 'preferences'. Adding 'needs' to the sentence does little to expand its scope.
NALC	Page 63	Information should be available in both written, verbal or	Agree. The text has been amended to make this clear.

		alternative formats, as appropriate to the patients needs.	
NALC	Page 64	Is it intended to provide describe videotapes for VIP patients?	
NALC	Page 65	It is essential that criticism by a small minority of patients/professionals should not be allowed to effect issue of this information	This is simply a summary of key evidence.
NALC	Page 66	The inability of some patients to return to paid employment should be discussed, failure could lead to family decisions being made in ignorance of probable outcomes.	This is simply a summary of key evidence.

NALC	Page 67	Patient *and Carers* must receive information of support groups, even if they see no immediate need for contact. ? trained ex-patients will funding be available to undertake this training.	This is simply a summary of key evidence.
NALC	Page 69	Some would argue that referral to addiction services at this point could be counter productive, 'blame' culture can increase depression for some patients.	The point is understood. However, our text puts the emphasis on offers of help or access to services which seem relevant to this patient group.
NALC	Page 70	Dental care after treatment – essential from trained experts-hospital unit – Free in line with free prescriptions	This comment refers principally to care after treatment and we have ensured that dental hygiene is an issue for the local support team looking after these patients in the longer term. Obviously specialist dental support is necessary for patients having radiotherapy in areas likely to cause dental problems as a consequence of treatment and this is emphasised in Topic 5 on Primary Treatment.
NALC	Page 71	2nd para end and swallowing should be added. Information on reconstructed puree meals should be made available prior to discharge	We are not entirely clear about the meaning of this comment. A point has now been added in Topic 5, where we consider that it fits more appropriately. The sentence now reads: 'Patients and their carers should be given guidance on the preparation of purée meals before discharge from hospital.'
NALC	Page 72	– Evidence 2nd para 'clinically depressed' – is any research planned into status before diagnosis?	The question of further research is not within our remit.
NALC	Page 73	1st para should include delays experienced in some centre in accessing CVT and MRI Scanning.	The evidence section is only intended to describe briefly some of the key features of the research evidence. Fuller evidence is available in the document on research evidence. It is not relevant to include a reference to variable delays in accessing scans.
NALC	Page 75	Final line counselling and training i.e. lip reading ..can be useful for carers, The need to provide specialist support for children should be included.	This is a generic issue, not specific to these cancers.
NALC	Page 76	Preparation for Laryngectomy ? Speech Training By Laryngectomee???	No comment required.
NALC	Page 79	video tapes ? visual impaired description tapes.	The thrust of this recommendation is clearly directed at patients receiving information of a range of types and media. It is inappropriate in a broad recommendation to deal with nuances of individual disability.

NALC	Page 80	3rd paragraph should recognise the impact of Primary and Secondary Trusts of a failure to ensure costs are shared throughout network and beyond.	This issue is addressed in our recommendations on commissioning which are designed to ensure that commissioning decisions are considered on a Network basis.
NALC	Page 82	3rd para Patients should have access amend to Patients must have access – this Statement should be included in final recommendations – and a requirement for all networks.	The point of view behind this comment is well understood and has been aired before. In terms of the language of service guidance we prefer to stay with our use of words.
NALC	Page 85	see page 38 and 2nd para last sentence and final para page 90 should be highlighted Staffing and machine provision MUST be addressed as a matter of urgency in ALL networks, lack of priority for H&N patients MUST be addressed in final recommendations.	The cost implications of the guidance are considered in the Economic Review; a draft will be available at the next consultation.
NALC	Page 90	Macmillans 'Spend It Where it's Meant' indicates that in some areas funding made available to improve access to radiotherapy would not appear to be reaching this service.	No comment required.
NALC	Page 93	Bullet point before Process add peer support for patients and carers 2nd last bullet point 'Evidence that appropriate care *including resuscitation training* and rehabilitation'	The term 'appropriate care' would include such things as resuscitation training. This is felt to be a point of detail too far. The addition of peer support for patients and carers is covered in the recommendations already. The developers feel that the list of structure measures is already fairly substantial, as are the process measures in this document. It would not be desirable to proliferate further measures to cover absolutely everything that has been dealt with in the text. It is accepted that this is a matter of judgement.
NALC	Page 99	2. + carers	This is a quote from the guidance for 'Improving Supportive and Palliative Care for Adults with Cancer'.
NALC	Page 100	2nd paragraph Primary and Secondary Care Trusts should ensure that ALL staff are aware of the need to access advice from the network.	MDT management should ensure that the patients are properly managed. This section relates to specific circumstances only. The text has been amended to make this clearer.
NALC	Page 103	3rd paragraph Supportive and Palliative Care Guidance? NICE	This refers to 'Improving Supportive and Palliative Care for Adults with Cancer', published by NICE in March 2004.
NALC	Page 104	despite NALC district/community nursing video still lack of knowledge in PCT teams	No response required.

NALC	Page105	additional bullets benefits advisor specialist self help group lip reading support for carers/family	These are sources of advice via the support team, that patients should be able to call on – already adequately covered in the text.
NALC	Page 107	3rd para assessment *and ongoing treatment* to ensure dental health	Text has been added on dental care.
NALC	Page 108	2nd para Valve replacement and neck breather training should be enhanced..to ensure 24 hour cover, direct access protocol should be drawn up, to ensure reduction of A&E events.	Please clarify what this refers to – (?) not relevant to this section.
NALC	Page 109	2nd paragraph ?ROM exercises. 3rd para ? patients with transport problems don't understand the reference 4th para communicated in writing –Newcastle's Joint Advisory group recent speech report highlighted that this was not an acceptable means of communication for disabled people	What is the issue? This has now been deleted. This is a report of the evidence, not a recommendation.
NALC	Page 110 ?	? 2nd paragraph.	It is unclear to what this comment refers.
NALC	Page 111	Typo in para 4 Laryngectomees Para 5 needs expanding to include patient/carer involvement in benefits advice, staff training, information production etc.	This has been corrected. This is a generic issue; too much detail for site-specific guidance.
NALC	Page 112	2nd para – don't understand the term social nursing provision	This was the term used in the report of the study from The Netherlands.
NALC	Page 113	3rd para This MUST BE AN ABSOLUTE minimum requirement highlighted in executive summary.	This is the Evidence section, not a recommendation; please clarify.
NALC	Page 95	I have a personal interest in the condition hypoparathyroidism any further info would be appreciated especially link to H&N cancer,	Not within the remit of this guidance.
National Cancer Alliance			This organisation was approached but did not respond.
National Cancer Network Lead Clinicians Group	Foreword	The combination of lack of evidence for reconfiguration, proposed concentration due to rarity, desire for local services where possible and the'flexibility for implementation….service pattern' has potential to make implementation difficult.	Agreed. No amendment required.
National Cancer Network Lead Clinicians Group	Key recommendations	The first recommendation on concentration in centres is not reflected in the text. It is not elsewhere clarified that specialist teams should operate at a single site. Is this the intention or are more dispersed models regarded as acceptable?	The wording of the key recommendations has been substantially revised.
National Cancer	Referral	Coordination through a single designated lead clinician at each	The guidance does not specify who should undertake

Network Lead Clinicians Group		DGH is welcomed. However, clinicans with differing expertise may be reluctant to refer patients to another consultant for a biopsy which they might previously have done themselves. Would it be acceptable, and perhaps preferable for all cases for biopsy to be reported to the lead clinician and discussed at the MDT.	the biopsy; does not have to be the designated lead clinician.
National Cancer Network Lead Clinicians Group	P32	Under the section 'patients with neck lumps', we believe there is a conflict with the haematological cancers guidance which suggests that other systems should be investigated prior to biopsy if it is thought that the cancer may originate outwith the lymph nodes. The role of endoscopy and core biopsy should be considered as FNAC is useful for squamous and thyroid cancer but not for lymphoma. Core biopsy offers an effective way of diagnosing a wider range of conditions. Lung cancer and TB also need to be considered in this context.	The text on lump clinics has been changed; the main text is in Topic 3: Initial investigation and Diagnosis New text has also been drafted to be consistent with the 'Improving outcomes' guidance for haematological cancers.
National Cancer Network Lead Clinicians Group	P32	If FNA is to be used, we think that ultrasound-guided techniques should be preferred. Refs. I A Robinson et al, Cytopathology: Vol 13, issue 6, page335, December 2002. I A Robinson and N J Cozens, Clin Radiol, 1999, vol 54, 312-316 and ibid vol 55, 327-328.	The following phrase has been added to the text: 'ultrasound guidance is a useful adjunct to either FNA or needle core biopsy and its use is expected to increase.' The technique of choice (FNA versus biopsy) will depend on the clinical situation and the suspected diagnosis (as well as clinical skills available in that place at that time). Further detail not appropriate here, as these are not clinical guidelines.
National Cancer Network Lead Clinicians Group		The internal consistency of incidence, population size and specialist MDT configuration should help to avoid some of the confusion encountered in implementing the urology guidance.	No response required.
National Cancer Network Lead Clinicians Group		We question whether a fortnightly meeting would enable the cancer waiting times targets to be met.	This text has now been amended.
National Cancer Network Lead Clinicians Group		Whilst arrangements for contacting the patient's GP are specified, no arrangements are indicated for informing the patient.	There is a section on the 3rd page of this topic dealing with this issue.
National Cancer Network Lead Clinicians		The draft guidance refers to the offer of an audiotape for key consultations. Written information is referred to later but it might be helpful to refer to the individualised letters to patients initiative	Reference has now been made to this initiative.

Group		which is now being promoted.	
National Cancer Network Lead Clinicians Group		There are references in both sections 4 and 5 to 'specific expertise', e.g. for MDTs handling base of skull tumours (bottom of page 69) and for salivary gland tumours and base of skull (page 80). Such expertise is currently self defined and vulnerable to such claims of expertise despite low volumes and/or poor or no reported results. Such definitions must include active and attending membership of a relevant MDT and may usefully include a minimum volume of activity below which the maintenance of expertise is unlikely.	Skull base surgery is only possible where there is both neurosurgery and H&N cancer centre services. This limits the options. Networks should therefore review their options and establish a clear referral policy with a centre with the clinical resources and expertise to manage these patients appropriately. The heterogeneity of these patients makes quoting numbers particularly problematic even if there were evidence – which there isn't. For salivary tumours there is a significant benign workload (particularly pleomorphic adenomas in the parotid gland) which do not need to come to the MDT. These can receive surgery in the periphery provided there is both access to FNAC and available interested and trained surgeons (ENT, maxillofacial or plastic surgeons in the main). Suspected or confirmed malignant cases should be referred to, and treated by, the relevant specialists in the MDT as we recommend.
National Cancer Network Lead Clinicians Group		Here we refer to statements on pages 46 and 80 regarding the provision of care in specialised head and neck (cancer) wards after surgery. This does not currently exclude a dispersed model of provision, albeit with centralised MDTs. Clarity on the desire for centralisation is required, if that is intended. For the specific post-operative care issue, perhaps it is nursing care needs and skills which should be pre-eminent rather than physical structure, as appears to be the case in the haematological guidance.	The reference to specialised head and neck cancer wards is a theme that has come through in both expert comment and patient comment. It concerns the skilled management of complications and other aspects of ongoing management which appear not to be well or reliably delivered in a non-specialist ward environment. The issue clearly has much to do with accumulated skills of nursing staff and some other disciplines including junior medical staff. There is no fundamental conflict here since radical surgery is intended to be centralised where the surgery is complex or difficult. This is consistent with the location of these patients in a dedicated ward rather than being dispersed within the hospital.
National Cancer Network Lead Clinicians Group	Page 85	Regarding radiotherapy, we seek greater clarity regarding the time and dose references.	It is assumed that this comment refers to the descriptive narrative on the evidence given in the manual. These are clearly important issues which is why the evidence is summarised to this degree. The fuller evidence and

			references will be available in the next round of consultation in the draft Evidence Review. If necessary, further elaboration can then be requested.
National Cancer Research Institute (NCRI)			This organisation was approached but did not respond.
National Council for Disabled People, Black, Minority and Ethnic Community (Equalities)			This organisation was approached but did not respond.
National Council for Hospice and Specialist Palliative Care Services			This organisation was approached but did not respond.
NHS Information Authority DAHNO Project (National Head and Neck Cancer Audit)	Page 8	We acknowledge and welcome the comments on page 8 – "data collection services require development and expansion"	No response required.
NHS Information Authority DAHNO Project (National Head and Neck Cancer Audit)	Page 29	The document has failed to report the transition from the BAHNO dataset to the National Cancer Dataset for Head and Neck 2002 endorsed by the DoH/NHSIA. Contribution to comparative audit in head and neck cancer is now co-ordinated by DAHNO (Data for Head and Neck Oncology) – a National IT Infrastructure project supported by the professional bodies / CHI / DoH / NHSIA. This has focused in its first phase outputs on initial treatments in oral and laryngeal cancers. The infrastructure will be available across England by December 2004.	Appropriate references have now been included to DAHNO.

		Further details can be found at: - www.nhsia.nhs.uk/ncasp . It would be helpful if this could be quoted in the Improving Outcomes Guidance Document. We strongly advise that contribution to National Comparative Audit is a minimum standard for all Head and Neck Cancer teams.	
NHS Information Authority (PHSMI Programme)			This organisation was approached but did not respond.
NHS Quality Improvement Scotland			This organisation was approached but did not respond.
Norfolk and Norwich University Hospital NHS Trust			This organisation was approached but did not respond.
Novartis Consumer Health (Novartis Medical Nutrition)			This organisation was approached but did not respond.
Ortho Biotech			This organisation was approached but did not respond.
Prodigy			This organisation was approached but did not respond.
Royal College of Anaesthetists			This organisation was approached but did not respond.
Royal College of General Practitioners			This organisation was approached but did not respond.
Royal College of General Practitioners Wales		Please note that the Royal College of General Practitioners will not be commenting on this guideline at this time.	This organisation responded and said that it has no comments to make.
Royal College of Nursing	Page 8	Bullet 3 – include physiotherapists and occupational therapists	The wording of the key recommendations has been substantially revised.

(RCN)			
Royal College of Nursing (RCN)	P26	Spelling larynd should read larynx	Amendment made.
Royal College of Nursing (RCN)	P36	Reference for Brazilian study	Included in the Research Evidence, available with the second draft.
Royal College of Nursing (RCN)	P36	Reference for the UK feasibility study of oral mucosa	Included in the Research Evidence, available with the second draft.
Royal College of Nursing (RCN)	P43	Should include physiotherapists	It is not expected that they would be required to attend every meeting, but only those where their expertise is required.
Royal College of Nursing (RCN)	P56	Would be happy to assist with compilation of this information	The Economic Review will be available at the second consultation.
Royal College of Nursing (RCN)	P62	"Breaking bad news" to be included as well as general communication skills	This is now included.
Royal College of Nursing (RCN)	P63	Use of qualified interpreters	This is a generic issue for hospital services, and does not just apply to head and neck cancer patients.
Royal College of Nursing (RCN)	P73	Reference of CXR v CT study	All studies used in the evidence review are fully referenced in the evidence review document, available at the second consultation phase.
Royal College of Nursing (RCN)	P93	Education to be included as well as research and development	There are a huge number of issues which could be subject to audit and measurement. The published list could be elaborated almost indefinitely. A sentence has been added to the end of the Background section as follows: 'The variety of issues that could be included is almost infinite and a wide range of additional issues could be monitored, some of which will have particular relevance to specific population groups or areas… the necessarily limited list given should not be regarded as complete.'
Royal College of Nursing	P108	This should include manual lymph drainage for lymphoedema and intervention for shoulder problems post- neck dissection	Included generically under 'complications'.

(RCN)			
Royal College of Nursing (RCN)	General	There is no inclusion of specialist catering services this is vital to ensure head & neck patients receive appropriate meals once specialist dietary advice has been sought	The paragraph on dietetic support has been extended to read as follows: 'There should be specialist dietetic support on wards where patients with head and neck cancer are nursed. The dietitian, ward nurses and specialist support staff should work with catering services to ensure that high quality food is provided in a form that meets the individual's requirements.' In addition, a paragraph has been added to the evidence section describing the findings of the NCA report on this point.
Royal College of Nursing (RCN)	General	PEGs are not a new intervention for head & neck cancer patients and should be the first line of intervention pre-operatively and for nutritional compromised patients requiring RT	The text on nutrition has been substantially re-drafted.
Royal College of Nursing (RCN)	General	The resource implications do not appear to have been addressed throughout the document. It is fairly self-evident that these are going to be high in terms of cost and time if the guidelines are to be met in full by the cancer centres, not least in terms of staff education and education provision. It therefore needs to be resourced effectively. We would be very happy to be involved in this part of the consultation.	The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation.
Royal College of Nursing	General	The clinical nurse specialist has an enormous role and the implication for that is potentially that even a small district general hospital will need possibly about two or three clinical nurse specialists to fulfil the role that has been put forward. Obviously the nurses are there almost from diagnosis to the whole treatment. But what is not highlighted or mentioned is that on the wards and within those departments, there will be head and neck trained nurses who will also be able to do some of this role. So we need to look closely at what is expected from the clinical nurse specialist and what is expected from head and neck trained nurses on the ward.	The text on the role of the clinical nurse specialist has been substantially re-drafted.
Royal College of Paediatrics			This organisation was approached but did not respond.

and Child Health			
Royal College of Pathologists	General	The implications of the head and neck cancer service guidance are that all squamous cell carcinomas of the head and neck region, all thyroid carcinomas and all salivary gland malignancies, generated by the cancer network, should be centrally reviewed. This has considerable resource implications for histopathology and cytopathology and needs to be carefully considered in terms of financing and consultant recruitment.	The draft of the economic review is available at the second consultation.
Royal College of Pathologists	Section 2 (page 46)	Review of head and neck cancer biopsies, from all head and neck cancers within the network, by the MDT pathologists will significantly increase their workload. This must be recognised and resourced	Agreed. Economic review available at the second consultation.
Royal College of Pathologists	Section 3 (page 61)	Many DGHs do not have cytopathological expertise in the FNA diagnosis of thyroid tumours. Central referral of material for diagnosis rather than central patient referral for FNA would seem more cost effective but this must be resourced.	The wording of the next paragraph, which brings in the necessary expertise, has been amended.
Royal College of Pathologists	Section 5 (page 81)	Pathological assessment of head and neck resection specimens is a time consuming process both for pathologists and biomedical scientists. It is also complex and best carried out by specialist head and neck pathologists to obtain the most prognostic information from the specimen. This should be explicitly stated and resourced.	This comment is entirely accepted. The need for those involved having specialist interest in head and neck cancer is dealt with generically within the section on the formation of the multidisciplinary team. That includes histopathologists.
Royal College of Physicians of London	General	We are concerned that there is very little in the Guidelines on palliative chemotherapy for recurrent / advanced disease. Our impression is that these patients are largely undertreated when it comes to palliative treatment (in comparison with breast or ovarian cancer, for example). We feel that at least a paragraph on Palliative chemotherapy is necessary with a brief review of the evidence (similarly to the structure of the paragraphs on chemoradiotherapy). Palliative chemotherapy offers no survival advantage, but there is no evidence on whether it offers benefit in terms of symptom control and quality of life. Clearly, clinical trials are necessary to answer these questions as well as to test new drugs in this setting. We feel it is necessary to encourage development and participation in clinical trials for those patients.	The following wording is now included in the re-structured Topic 7, Follow-up and recurrent disease: Chemotherapy or chemoradiation is increasingly used, but reliable evidence of effectiveness is lacking and there is uncertainty about the overall impact on quality of life…. Research is urgently needed, especially to evaluate newer therapeutic agents.' A key recommendation has been added, emphasising the importance of research into the effectiveness of management, including clinical trials.
Royal College	General	In general the guidelines are comprehensive although not very	There has been considerable re-drafting of the section

of Physicians		detailed. The merging of Thyroid cancer in with other head and neck cancer may lead to some confusion as the management postoperatively is very different. There is almost no reference made to the 2002 RCP/BTA guidelines on the management of thyroid cancer which is disappointing and suggest that these guidelines have been written in isolation from existing guidelines. From the perspective of thyroid cancer there is an inadequate coverage of the debate about the extent of surgery in Medullary Thyroid Cancer and the issue of surgery in papillary carcinomas <1cm.	on structure of services, including that relating to thyroid cancers, and the thyroid cancer MDT. It should be remembered that these are not clinical guidelines; this is service guidance. A balance must always be struck between including too much (or too little) clinical detail.
Royal College of Physicians	p107	The text should read thyroglobulin OR calcitonin not thyroglobulin and calcitonin	The text has been re-drafted to improve clarity.
Royal College of Psychiatrists			This organisation was approached but did not respond.
Royal College of Radiologists			This organisation was approached but did not respond.
Royal College of Speech and Language Therapists	General	Comments that refer across several pages have page numbers in bold in the LH column	No response required.
Royal College of Speech and Language Therapists	General	Firstly, we would like to thank you to all who have contributed to this positive document, clearly a lot of work has gone in. While the impetus to improve services is clearly transmitted in the document, give that some of our members were involved in the original “proposal generating event”, we are very disappointed at the final result. ” Statements such as “appropriate care” (pp 93) and “sufficient numbers of appropriately trained staff” (pp 104) are vague and provide no clear guidance to those commissioning services on precisely what staffing and resources are required. References to SLT involvement focus heavily on total laryngectomy, and this is often implied/assumed, rather than specified (e.g. paragraph 1, pp106 section 8).	Thank you. See all responses to the points made. There has been considerable re-writing and re-drafting of the text following the first consultation; it is hoped that these concerns are now addressed. The resource issues are addressed in the economic review; draft available for the second consultation. There has been considerable re-drafting and amplification of the text concerning the role of the SLT.

		There is no discussion of head and neck patients with a wide variety of voice and other communication disorders who have not undergone laryngectomy. The assessment and management of dysphagia is given scant reference, and the original specific recommendations for resourcing dysphagia clinics appropriately (through the timely provision of FEES and videofluoroscopy assessments) have been deleted. This is a significant oversight, as these services are expensive and time-consuming but vital to the appropriate rehabilitation of the patient. The section on speech and language therapy (section 2, pp 48) is brief and vaguely written, in contrast to the clearly outlined role and expertise of the CNS. For example, SLTs work on total communication, not just "face-to-face communication" (section 2, pp 48). Overall, the Speech and Language Therapy staffing, resourcing and service requirements set out in this document would benefit from being re-written, to provide clear and specific guidelines for those commissioning services for head and neck patients, and we recommend RCSLT specialist advisors assist in the re write.	Aftercare and rehabilitation are now covered more extensively in a re-structured Topic 6. See response above. The balance has now been changed in the text, with additional information on roles, including that of the SLT, also included. The text on the role of the CNS has also been revised. A speech and language therapist was a member of the Editorial Board. Much of the writing and re-drafting have been undertaken with her help.
Royal College of Speech and Language Therapists	General	The whole document is CNS biased. This is disappointing when so much of the text refers to the whole multi disciplinary team. This gives the impression of a CNS bias which we consider to be contradictory to the ethos of multidisciplinary working. It appears that the authors in attempting to be concise have as a result, produced a document which fails to cover all issues in sufficient breadth / depth	See response above. The balance has now been changed in the text, with additional information on roles, including that of the SLT, also included. The text on the role of the CNS has also been revised.
Royal College of Speech and Language Therapists	General	We are disappointed that the QOL assessment is not given more prominence in this draft, particularly in pre-treatment stage to take base-line measurement, target appropriate intervention and inform patients on likely consequences of treatment proposed on both function and QOL. For example please see ch. 4.1 in BAOHNS effective Head and Neck Cancer Management 2003 by Simon Rogers and Kaye Radford. We would recommend that the guideline include more reference to this document.	There are a huge number of issues which could be subject to audit and measurement. A judgement has been made therefore to have a restricted list, but in order to reflect these concerns a sentence has been added to the end of the Background section as follows: 'The variety of issues that could be included is almost infinite and a wide range of additional issues could be monitored, some of which will have particular relevance to specific population groups or areas. Audit activity of this sort is valuable and the necessarily limited list given

			should not be regarded as complete.'
Royal College of Speech and Language Therapists	General	A number of studies are referred to in the text but not referenced which makes it impossible to access these for comparison - some of them appear quite obscure and largely irrelevant, for example references to studies in Switzerland where rehabilitation facilities are extremely limited in comparison with the rest of Europe We recommend that other up to date and more relevant references are considered for this guidelines, and have included references within our comments and at the end of this table	All the references used to support the guidance are included in the Research Evidence, available at the second consultation. Reference to the Swiss study has now been removed.
Royal College of Speech and Language Therapists	General	We appreciate that the guideline will be edited for consistency and highlight the following to assist with this The spelling of 'dietician' is incorrect and should be dietitian. Speech and Language Therapist are referred to using a variety of terms for example Speech therapist, SALT, Speech & Swallowing. We recommend the term Speech and Language Therapist (SLT), and Speech and Language Therapy is used throughout the document.	Now spelt consistently throughout. Agreed. This is now consistent (SLT throughout).
Royal College of Speech and Language Therapists	General	We welcome the stated incorporation of SLT as core members of the MDT, but are concerned that under key recommendations (p8) there is no mention of Speech and Language Therapists or Dietitians as <u>necessary</u> for MDT.	The wording of the key recommendations has been substantially revised.
Royal College of Speech and Language Therapists	General	It would be helpful to see an estimate of numbers of staff required per 1000 population as in other NICE guidelines.	This is the province of the economic review, a draft of which is available at the second consultation.
Royal College of Speech and Language Therapists	General	We are concerned that throughout the draft there is little written about physiotherapy input for neck dissection and that there is no mention of lymphoedema services.	Lymphoedema services are a generic issue for cancer patients, not just for head and neck cancers (see 'Improving Supportive and Palliative Care for Adults with Cancer' published March 2004). Reference is made to the role of the physiotherapist in the restructured Topic 6, Aftercare and rehabilitation.
Royal College of Speech and Language	Page 8	We are concerned that under key recommendations there is no mention of Speech and Language Therapists or Dietitians as <u>necessary</u> for MDT, only clinical nurse specialists. We are aware	The key recommendations have now been substantially re-drafted.

Therapists		that later on in the document, the importance of these AHPs is stressed, but mention in the key recommendations would ensure a consistent message is conveyed.	
Royal College of Speech and Language Therapists	Page 8	Data collection and research are seen as key to effective rehabilitation yet there is no mention of these in the speech and language therapy role. The laryngectomy dataset to include core aspects of laryngectomy rehabilitation is now nearly complete following the NHSIA pilot in conjunction with BAHNO. This could be listed as an essential part of the SLT role stating resources should be available for time to complete the dataset. Please see ch. 4.1 in BAOHNS effective Head and Neck Cancer Management 2003 by Simon Rogers and Kaye Radford	Further clarification of the role of the Speech and Language Therapist has been added. The DAHNO audit is also now referenced.
Royal College of Speech and Language Therapists	Page 9	We are pleased to note that this section is clearly written, provides a clear framework for both the services required, and the need for further, robust research into this area.	No response required.
Royal College of Speech and Language Therapists	Page 26 3rd	There is a typing error for Larynx Fibre-optic or rigid endoscopy is essential, so we recommend the second part of the second sentence is reworded to read ' …- the insertion of a fibre-optic or rigid endoscopy is essential.' - and 'Stroboscopic examination of the larynx is useful.' – is added	Amendment made. Agreed. Amendment made. Too much detail.
Royal College of Speech and Language Therapists	Page 27	We are concerned that there is no mention of wider patient and their carers & needs, for example psychological and financial needs / concerns We consider this to be especially important given that patients with Head &Neck Cancers are a particularly vulnerable group – due to premorbid problems e.g. alcohol addiction, low socio-economic status. There is evidence that social status, support, tobacco and alcohol addiction, depression etc affects outcome. (Please see references given at the end of this table). Head and Neck Cancers are not just about facial disfigurement but also body image e.g. significant weight loss, PEG/nasogastric tube feeding. Associated anxiety & depression is for a majority of patients	There is always a balance to strike between providing sufficient detail within the background section to orientate the reader, and including too much material. Most of the points identified here are covered in the later text. New text has, however, also been added.

		undetected, with only 30% of cases picked up by doctors and just over 50% by nurses. We are also concerned that no reference to sexual problems that may arise have been made in this guidance.	
Royal College of Speech and Language Therapists	Page 27	We are furthermore concerned that there is no mention of pre-treatment QOL measures being taken to establish base line to identify functional problems pre-treatment and for use in targeting appropriate rehabilitation/interventions.	This is covered in Pre-treatment assessment and management.
Royal College of Speech and Language Therapists	Page 28	SLT services vary in terms of staffing and grading across country for patients with Head &Neck Cancers. It would be helpful if Speech and Language Therapy figures for staffing and grading were included. There may be more statistical data from an audit by one of our members (regrettably unavailable in time for this response). We are more than happy to follow this up	Not appropriate for the Background section. Please send audit data as soon as possible.
Royal College of Speech and Language Therapists	Page 28	States, "Without a nationwide audit it is not possible to present a reliable snapshot of current services for patients with head and neck cancer". We support the need for nationwide audit of services (across the UK and not just England – although we appreciate NICE's geographical remit) as some of the references in the document appear outdated or of questionable relevance. The laryngectomy dataset will assist in this audit and we would recommend that NICE guidelines acknowledge this and recommend all units participate in the dataset.	The problem with compiling this guidance was the lack of appropriate evidence. No response required. This proposal is outside the remit of this Guidance.
Royal College of Speech and Language Therapists	Page 30	The referral recommendations are excellent. However we have concerns that for networks to decide which hospitals provide diagnostic service carries a big responsibility. Decision - making will need to be formally conducted in consultation with trusts delivering present services.	This will be the responsibility of networks.
Royal College of Speech and Language Therapists	Page 30	A further concern is that the needs of support staff will not be prioritised or considered as the networks tend to be medically dominated.	This is speculation; networks must decide how the services will be organised.
Royal College	Page 30	Speech and Language Therapists are still seeing patients in their	

of Speech and Language Therapists		units who present very late. The problem is not accessing the consultant but that the GP treats the patient who has hoarseness for several months with antibiotics etc before referring. Disseminating information to GPs does not seem to work. In an audit the patients' journey at one of our member's place of work, (and due for publication later this year), patients reported consistent delays in GP's referring to hospital. We would welcome that NICE recommend an audit of the delay between the patient first reporting hoarseness to their GP and the GP referring the patient to hospital, especially in the light of the government's referral – to treatment targets.	As the stakeholder points out, this is related to Government referral targets. The question of the time between a patient first reporting the symptom of hoarseness and referral by a GP is covered in the urgent referral guidelines. This proposal is beyond the remit of this Guidance.
Royal College of Speech and Language Therapists	Page 41	Again, networks need to do this with full consultation as above. We would welcome clarification on what will happen if present centres with rehabilitation teams do not have 1m population.	Agreed. Subject to local network negotiation.
Royal College of Speech and Language Therapists	Page 42	Many teams may not have CNS, so we consider it would be more useful if the skills and expertise required by the MDT could be expanded in the sections describing members of the various teams page 42 – 46, as well as the posts within MDTs. We would be pleased to assist with the information required for the SLT role.	The CNS is regarded as a crucial member of the core team.
Royal College of Speech and Language Therapists	Page 43	Physiotherapy needs to be included other the "Members of the Core Team"	It is not expected that they would be required to attend every meeting, but only those where their expertise is required.
Royal College of Speech and Language Therapists	Page 43	SLT section needs rewording with greater detail. In the first instance, we suggest that this is reworded to Speech and Language Therapist with expertise in patients with head and neck cancer patients. Speech and Language Therapists have a role in patient care pre-treatment as well as post – treatment.	Agreed. Further clarification of the role of the Speech and Language Therapist has been added.
Royal College of Speech and Language Therapists	Page 47	We agree that the CNSs play crucial roles in MDT meetings, both in discussion of management strategies for individual patients and by contributing to wider strategic planning and policy-making. Because of the nature of their relationship with patients, CNSs	The section on the CNS has been re-written, to emphasise the CNS's pivotal role, without going into too much clinical detail. The roles of other key disciplines have also been included.

		can often bring a richer understanding of patients' preferences, cognitive and coping skills, and a more detailed knowledge of their social situation, to the decision-making process.' and we recommend that the guideline emphasises this is not purely a nursing role or expertise. We have commented above on the apparent bias in presenting the CNS role in such detail compared to other members of the MDT. We also wish to emphasis that other members of the MDT possess and use these skills as well, in particularly SLTs. Many teams may not have CNS, please see comments for p42 – 6.	
Royal College of Speech and Language Therapists	Page 47 & page 52	These two sections could be put together as they appear repetitive and present the role of CNS in great detail compared to other MDT members. Also other members of the MDT have and use these skills – please see above comments	The text has been edited to remove repetition.
Royal College of Speech and Language Therapists	Page 48	Please see general comment about consistent terminology when referring to Speech and Language Therapist(s), Speech and Language Therapy. We are very concerned about the very limited definition / description of the Speech and Language Therapist's role, and recommend that this section The SLT section is rewording with greater detail. A year's experience is inadequate, and certainly no therapist would be considered "expert" after one year's experience.	The text is now consistent. The text on SLT has been re-worded.
Royal College of Speech and Language Therapists	Page 48	We suggest the following re – wording: "over a substantial time..often a year, sometimes even longer" –is ambiguous. We suggest the first sentence is reworded to " Speech and Language Therapy for people who have been treated for head and neck cancer demands a high level of expertise with significant postgraduate training. Re-word SLT role to "The SLT will be responsible for the assessment and management of communication and swallowing throughout the patient journey." And include	The section has been re-worded. The text has been revised on the role of the SLT.

		"Pre-treatment assessment should be conducted to identify problems with voice, speech and swallowing due to the presence of cancer and take base-line measures. Many patients may already have speech/voice swallowing problems". Pauloski BR et al (2000), Pre-treatment swallowing function in patients with head & neck cancer. Head & Neck 22:474-482, Stenson et al (2000). Swallowing function in patients with head & neck cancer prior to treatment. Archives Otolaryngology Head & Neck Surgery 126:371-377. Also add: The SLT should also assess literacy skills in preparation for alternative post-treatment communication, - (for example in the case of laryngectomy, glossectomy, and those patients unable to cope with surgical voice restoration), and cognitive skills relevant to decision-making and informed patient choice (for example patients who are unable to cope with considering surgical voice restoration, or for patients with partial laryngectomy and who may have to follow complex swallow commands	This section of the guidance seeks to clarify the roles of the MDT members; every detail of what they actually do cannot be included. See above – too much detail.
Royal College of Speech and Language Therapists	Page 48	We would like the guideline to emphasis that the SLT's role in rehabilitation is also psychosocially based as SLTs work on communication breakdown and in helping patients and their families adjust and achieve their maximum potential post treatment. Swallowing problems will also require psychosocial rehabilitation as eating and drinking are core to human interaction and socialising We would hope the guideline will reflect the broad scope of SLT intervention in that it may be non-oral (using aids) and that intent may not be rehabilitative but maintenance or palliation." For example SLTs working with patients with laryngectomy may keep patients on indefinitely for management of SVR programme. Also for some patients function may deteriorate over time	The text on the role of the SLT has been revised. More detail is in the Rehabilitation section.
Royal College		We have included some references for the above comment	

of Speech and Language Therapists		Wu et al (2000). Dysphagia after radiotherapy: endoscopic examination of swallowing in patients with nasopharyngeal cancer. Ann Otol Rhinol Laryngol 109(3):320-5 Chang YC. Chen SY. Lui LT. Wang TG. Wang TC. Hsiao TY. Li YW. Lien IN. Dysphagia in patients with nasopharyngeal cancer after radiation therapy: a videofluoroscopic swallowing study, *Dysphagia. 18(2): 135-43, 2003*	No comment required.
Royal College of Speech and Language Therapists		Also many SLTs are now involved in research or would like to be if the high workloads did not prevent this. Please see comment for p 108	No comment required.
Royal College of Speech and Language Therapists	Page .49	'Professions allied to medicine' is an outdated term, and Allied Health Professions is the current term.	Amendment made.
Royal College of Speech and Language Therapists	Page 49	The actual casenotes should be available at the MDT meetings, rather than copies, which we consider to be poor practice.	Amendment made.
Royal College of Speech and Language Therapists	Page 50	There is a typing error - 'be' missing before available. Laptop computer 'used' should be 'completed'. We suggest re-wording '.. ideally this should be available on a laptop computer so that it (the pro-forma) can be completed during the MDT meetings.' We consider information gathering and audit activities etc. should aim for direct inputting to database for real time data capture at source.	Amendment made. The point is about using the form electronically, so that it is always as up to date as possible.
Royal College of Speech and Language Therapists	Page 50	We recommend that 'as quickly as possible' is quantified.	Will depend on local circumstances.
Royal College of Speech and Language Therapists	Page 50	It is not clear if the staff mentioned here are clinical or administrative staff, and suggest the guideline clarify this	Will depend on local circumstances.

Royal College of Speech and Language Therapists	Page 52	We support the statements about the role of the CNS, and agree that patients often feel happier talking to non-medical staff, but it is not only CNS's who have this ability and expertise. We would like to emphasis that this also applies to SLTs, (especially for patients with communication needs), and probably other members of the MDT. We recommend the guideline is reworded to reflect this. Please also see comments for p 47 & p 52	Section re-worded to reflect changes to recommendations.
Royal College of Speech and Language Therapists	Page 58	We are concerned about the limited information regarding structure, which is not just not just CNS and should reflect all care members of the team including SLTs	Text revised.
Royal College of Speech and Language Therapists	Page 58	It is not clear how participation (other than attendance) will be measured. We would not consider attendance to be a sufficient measure for participation.	To be defined locally.
Royal College of Speech and Language Therapists	Page 59	The guidance is very much focussed on CNS possibly to the detriment of AHPs who have a significant role to play in the multidisciplinary care of patients. We recommend that 'and dedicated specialist head and neck cancer SLTs' is added Many more SLT's are required, in addition to the stated need for more CNSs. For example one of our members noted that in the team she works in there are 2 CNS's in our team and NO funded SLT time We would very much welcome clarification of how the resource implications will/ should be managed for implementation of this guideline.	A generic statement has been added to the resource implications This is an issue for the DH, cancer networks and service commissioners.
Royal College of Speech and Language Therapists	Page 62	It would be helpful for the guideline to indicate where / who could be approached for training in ' breaking bad news'	This is too much detail for this guidance.
Royal College of Speech and Language Therapists	Page 62	We suggest adding ' … sensitive to individual patients coping style' (ref. De Leeuw 00 positive and negative effects of information;	This point is already covered in para 3.

		Miller 95-coping styles)	
Royal College of Speech and Language Therapists	Page 63	There is reference to friendship schemes for patients who will have problems with speech. We consider this primarily refers to the laryngectomy visitors scheme, and recommend that such schemes are encouraged and promoted in other areas of head & neck cancer for patients who have functional loss. The laryngectomy club has produced some very good written information, but it is lacking in other areas.	No amendment proposed – the text is sufficiently broad in scope already.
Royal College of Speech and Language Therapists	Page 63	We are pleased to fully endorse this	No response required.
Royal College of Speech and Language Therapists	Page 63-64 & 5, Page 70	It is important however, that patients should have a real choice of whether to avail themselves of these options regarding meeting others. There are 2 papers suggest some patients do not cope with this well – please see references at the end of this table	The wording 'option of' has been added.
Royal College of Speech and Language Therapists	Page 63-64 & 5, Page 70	There will be resource implications for training patient visitors, which are not fully articulated in the guideline.	Only the larger cost impact issues are addressed.
Royal College of Speech and Language Therapists	Page 63-64 & 5, Page 70	We recommend that patient visitors should be available to all Head &Neck patients and not only new patients	The text does not preclude this.
Royal College of Speech and Language Therapists	Page 65	We would like to strongly emphasis that SLT's have the skills and information to support and explain the communication and swallowing implications of these procedures as we are trained in communication and eating and drinking. We suggest that time is spent in the MDT discussing and agreeing the information to be explained to patients and that explanations are given by the most appropriate person in the MDT, which although in practice might be the CNS, may not always be the case. Please see comments for p 47, p52. Please see Stam 91, Stafford N, 2001, de Leeuw and de Graeff 00 for further reference on information-giving	The role of speech and language therapists is given prominence in this document and we are pleased to see that this is strongly supported by the professional association. Stafford N, 2001 and de Leeuw and de Graeff 00 were assessed as part of the evidence review.

Royal College of Speech and Language Therapists	Page 66	Please see Nick Stafford 2001 a further reference on surgeons practice	This paper is a description of a survey of current practice; not included in the research evidence for this guidance.
Royal College of Speech and Language Therapists	Page 67	We would suggest the guideline promotes the necessity to have careful choice and supervision of trained visitors and ex-patients for the purpose of patient support groups (and patient visitor schemes (p 63)	This issue is already adequately covered in the text.
Royal College of Speech and Language Therapists	Page 70	See comments regarding CNS bias	The balance has now been changed in the text, with additional information on other roles now included.
Royal College of Speech and Language Therapists	Page 70	Please see comments for page 78	The Measurement Process final bullet point has been modified to read: 'Evidence that patients whose treatment is likely to involve the jaw are referred to appropriate disciplines such as dental specialists, speech and language therapists.'
Royal College of Speech and Language Therapists	Page 71	Modifications to food consistency is where dietitian & SLT often crossover, and we strongly recommend that the close working relationship between these 2 AHPs is emphasised.	This point is similar to comments made by others and is accepted. The text has been revised accordingly.
Royal College of Speech and Language Therapists	Page 71	Paragraph two states that the SLT will work with the patient to restore speech. The description of SLT role preoperatively is very disappointing and extremely limited. This ignores the overall rehabilitation of communication in total, and there is no mention of swallowing assessment or rehabilitation. SLTs are often far more involved preoperatively than any other single profession and we would not only explain but involve patients and carers in joint decision making help to help them make informed decisions about communication and swallowing. Our role would also include psychosocial counselling and support around communication and swallowing problems. This role is only described as part of the nursing role. However, SLTs are likely to see patients more intensively compared to nurses who often are involved in the acute stages then have limited input. SLTs are involved in longer -	The nature of this comment is well understood and appreciated. The revised text does seek to give a better balance and also emphasise the collaborative multidisciplinary nature of the input involving the SLT and others at this stage.

		term rehabilitation sessions often on an intensive basis and the support and psychosocial aspects are a key part of assessment and therapy.	
Royal College of Speech and Language Therapists	Page 71 paragraph 2	We suggest re-wording restore to 'optimise' (as it is not always possible to restore). We suggest that 'voice, and swallowing' after speech, and she/he. So that the last clause of the last sentence reads … and describe how she / he will work with the 'patient to optimise speech voice and swallowing	This comment has been made by others and we have revised the relevant text. The current draft now reads as follows: 'The SLT…will work with the patient to make the most of his or her potential for recovery of speech, voice and swallowing.'
Royal College of Speech and Language Therapists	Page 76	We are concerned that laryngectomy preparation appears to be treated separately to other head and neck surgery or treatment. SLTs work with a wide variety of head and neck patients, not just total laryngectomy, and this is overlooked in this section and elsewhere in the document (e.g. p 106, Section 8).	This comment is fair in identifying an unintended distortion in the text. Emphasis has been given in re-drafting of other sections to a more broadly-based sense of the contribution made by speech and language therapists.
Royal College of Speech and Language Therapists		With regard to the focus group study finding counsellors did not help but wanted the patient to find solutions rather than listen to them, we considered this to be a sweeping statement given the different approaches to counselling. It would be interesting to know the counselling approach used by the counsellor(s) in this study. Some counselling approaches may be inappropriate to people experiencing traumatic experiences, for example those that seek to get the person to reconstrue their trauma despite the counsellor having no personal understanding of how horrendous this disease can be. We therefore welcome the recommendation for trained patient volunteers. We would suggest person centred / Rogerian type counselling approaches might be more applicable to this patient group especially in the acute stages, rather than for instance cognitive behavioural therapy. We would welcome a recommendation that all specialist nurses and rehabilitation team members have person centred counselling	These comments are noted. They are predominantly concerned with commenting on existing evidence. The descriptions of the specialist roles of a number of disciplines in supporting patients with major problems makes it implicit that these patient volunteers will have appropriate professional training development and supervision. It is not necessary in the guidance to specify how each of the competencies of these individuals will be dealt with.

		skills training to support people informally and to allow them space / time to talk incidentally in an accepting environment as they need it as well as having access to more substantial counselling/clinical psychology services.	
Royal College of Speech and Language Therapists		We are surprised that this Swiss study is quoted and consider it a very odd one to quote as there is no comparability with other countries' rehabilitation services. 'Many of these interviewees suggested that speech training should be conducted by laryngectomees'. We consider this to be a very sweeping statement with no evidence to support it. We wonder if this recommendation is because maybe there was no SLT available. We do not consider this recommendation to be relevant in today's surgical voice restoration climate.	Reference to the Swiss study has now been removed, and the text modified.
Royal College of Speech and Language Therapists	Page 78	We are concerned that for patients likely to receive treatment that could affect the jaw or teeth there is no mention of SLT/dietitian. We recommend that 'specialist SLT and dietitian' is added at the end of the sentence	This point has been made by others and will be included in the revisions to this section.
Royal College of Speech and Language Therapists	Page 80	We wholeheartedly support the recommendation that surgical voice restoration should be available. ". There are many studies in the literature that highlight the success rate of SVR in intelligibility compared to other methods of communication but none of these studies are cited in the document, for example Clements, Rassekh, et al, Communication after Laryngectomy an Assessment of Patient Satisfaction Arch Otolaryngol Head and Neck surgery Vol 123 May 1997 pp 493 – 496; Max L, De Bruyn W and Steurs W, Intelligibility of oesophageal and tracheo –oesophageal speech: preliminary observations. European Journal of Communication Disorders 1997 Vol 32 pp 429-440; Bertino et al Spectographic Differences between Tracheal – Esophageal Voice and Esophageal Voice. Folia Phoniatra Logop	The issue of the effectiveness of SVR was not one of the research questions. The Editorial Board considered it to be the 'gold standard'.

		1996; 48: pp 255-261.	
Royal College of Speech and Language Therapists	Page 80	Units should be shown to be offering SVR to the majority of patients. The Laryngectomy dataset will collect success rates using basic outcome measurements if units comply with completing this dataset. There is also evidence in the literature regarding the success rates of primary compared to secondary SVR and if these were cited it could mean NICE could recommend primary SVR as the gold standard for rehabilitation. See for example Trudeau MD, Hirsch SM and Schuller DE Vocal Restorative Surgery: Why Wait? Laryngoscope 1986 Sep; 96 (9Pt1) pp975- 7. There is also evidence emerging in the literature re voice prosthesis type and the potential for complications i.e. that wider diameter valves could be linked to the tracheoesophageal puncture widening which is a very serious complication. For example Issing WI, Fuchshuber S and Wehner M Incidence of tracheoesophageal fistulas after primary voice rehabilitation with the Provox or the Eska- Herrmann voice prosthesis. Eur Arch Otorhinolaryngol (2001) 258: 240-242. Blom E Some Comments on the Escalation of Tracheosophageal Voice Prosthesis Dimensions Arch Otolaryngol Head and Neck Surgery Vol 129 Apr 2003 p 500 - 502. One prospective study showed there to be no difference between one voice prosthesis and a more expensive alternative. Delsupehe K, Inge Zink, Maryline Lejaegere and Pierre Delaere Prospective Randomized Comparative Study of Tracheoesophageal Voice Prosthesis: Blom Singer versus Provox Laryngoscope 108: Oct 1998 p 1561- 1565. It would very useful if NICE could include these studies as consideration of these issues could make a big difference to the rehabilitation of laryngectomees.	The issue as to whether to say any more about SVR in the text, which has come up in many comments, will be further considered following the web consultation.

Royal College of Speech and Language Therapists	Page 80	We are aware of several centres who offer no or little SVR and several who do not offer primary SVR. Any SVR programme needs to offer with be well-resourced rehabilitation service and equipment. Our concern therefore is that the recommendation for SVR availability fails to consider the resource implications to deliver such programmes. SVR programmes require significant on-going personnel and equipment and therefore a dedicated budget for long-term patient support will be required	The short paragraph on surgical voice reconstruction has been reviewed, and text added to the recommendations and measurement sections. Resource implications are part of the economic review.
Royal College of Speech and Language Therapists	Page 81	The recommendation that the gap between surgery and radiotherapy should ideally be no more than 6 weeks will be a major problem in units where patients wait for longer. It would be especially useful if this were to be a key recommendation and could be audited nationally.	This issue is clearly dealt with in the recommendations and the issue of delay is dealt with in the Measurement section on audit.
Royal College of Speech and Language Therapists	Page 82	We consider management of mouth care to be a multi-disciplinary responsibility and account needs to be made of individual patient difficulties e.g. treatment approach/dentition etc.	These issues are covered in the document in a number of places.
Royal College of Speech and Language Therapists	Page 82	Include voice so that the first clause reads 'Radiotherapy for head and neck cancers can cause problems with eating, swallowing, breathing speech and voice …'	This comment has been made elsewhere and is accepted. The text has been changed.
Royal College of Speech and Language Therapists	Page 83	We welcome the recommendation for research. However, research components to jobs will have implications and needs to be built in to all job descriptions of core members of the MDT and the time needed for research appropriately accounted for when considering staffing requirements for MDTs etc. see also comments for page 108.	We believe it is important to stress the importance of research and the development of a better evidence base for practice and for future service organisation. How that agenda is taken forward and by whom is a matter which goes beyond our specific remit.
Royal College of Speech and Language Therapists	Pages	The statement "commissioners should ensure that such development is possible through the provision of in-house facilities or links with appropriate organisations" is, in our opinion, too vague and will let commissioners "off the hook" in providing structured R&D support. It would be more helpful if the guideline state specifically that medical statisticians should be employed and available to support the MDT in designing and participating in research.	This document has made recommendations which are designed to encourage those responsible for research, both nationally and more locally to consider this in the context of head and neck cancers. It is not felt appropriate for this guidance to go into specific detail about precisely how that should be achieved.

		Much of the poor research currently published is, in large part, due to the lack of available statistical support in research design and analysis.	
Royal College of Speech and Language Therapists	Page 89	We wholeheartedly agree with this.	No comment required.
Royal College of Speech and Language Therapists	Page 92	Please see general comments about consistent terminology for Speech and Language Therapist (SLT), Speech and Language Therapy. We consider this to be vague – we suggest rewording 'speech and language therapist with specialist experience in speech and voice rehabilitation including SVR as well as swallowing and eating difficulties'	This bullet point has been re-drafted to read as follows: 'Availability of support for patients undergoing treatment, including access to a CNS, a suitably specialised and experienced head and neck dietitian, and a speech and language therapist with specialist experience in all forms of speech and voice rehabilitation and management of swallowing and eating difficulties.'
Royal College of Speech and Language Therapists	Page 92	This is limited and we suggest adding SLT involvement to assist patients in for example using valves, and using them effectively and appropriately, taking all aspects of communication into consideration	See response above, which covers this.
Royal College of Speech and Language Therapists	Page 93	This needs to include weekend and out of hours advice and support for SVR as well as breathing and swallowing problems. SVR problems include leaking voice prostheses, inhaled voice prostheses etc. The SLT should train nurses and junior medical staff etc. to carry out basic out of hours troubleshooting. Such training should be regarded as essential and ongoing rolling training programmes should be planned as staff rotate and change.	Text added to recommendations to cover this point; also a new bullet point in the measurement section: Provision of ongoing rolling training programmes for nurses and medical staff, organised by the specialist SLT, in dealing with common problems associated with surgical voice restoration or other effects of treatment on breathing and swallowing.
Royal College of Speech and Language Therapists	Page 93	It is not clear how adequacy of surgery will be measured. We would recommend that audit of functional outcomes and audit of QOL measures is added.	This comment has been made by others and partially accepted. Audit of functional outcomes after surgery has now been added. However, 'audit of QOL measures' seems so vague as to be virtually meaningless; also, QOL at this point in the patient journey is more likely to reflect the extent of surgery than anything else. This has therefore not been included.
Royal College of Speech and Language Therapists	Page 93	We wonder why are other patients not included in the need for evidence as all groups would need rehabilitation. It would be helpful if this criterion could apply to all types of patient i.e. evidence of rehabilitation is necessary.	It is helpful if Process points are reasonably precise as it is almost impossible to monitor or measure a very heterogeneous group of needs (as is being suggested here).

Royal College of Speech and Language Therapists	Page 100	The suggestion that patients with acute airway obstruction are admitted directly to a ward and not A&E is a risk. This suggestion could cause problems if the airway obstruction were caused by other medical problems. There might be no doctor present on the ward, or out of hours only nurses and it may not be clear that the patient has a mucus plug blockage or the problem could be related to an MI etc. rather than stoma related. There may also be no facilities to deal with a haemorrhage etc. from the stoma on the ward compared to A&E. Ward patients may already be taking staff time and there may be no time to allocate to an emergency brought to the ward unannounced. There is also no evidence in the literature to support this recommendation and consensus between professionals has not been assessed. We consider that it is essential for all A&E staff and paramedics to be trained and aware of stoma care and blockage and we would welcome the recommendation that this training is essential.	The intention is for appropriate patients to be able to go straight to the ward. Patients in the example quoted would go to A&E. The wording has been revised from 'patients with acute airway obstruction are admitted' to patients with anticipated acute airway obstruction can be admitted'. Training emergency staff in the management of emergency conditions is a generic issue.
Royal College of Speech and Language Therapists	Page 101	Another problem is that 999 ambulances take patients to the nearest A&E not to a hospital with an ENT department. There appears to be no way of getting around this legally. It would be more useful for the guidelines to suggest taking these patients to an A&E dept within a hospital with ENT facilities rather than just the nearest A&E, which is usually the case. We have examples of inappropriate management of my laryngectomees when they have been admitted to A&E in hospitals without ENT backup. NICE recommendations would be a potential way to get ambulance services to take head and neck patients with acute problems to a hospital where appropriate clinical staff can be available to go to A&E.	The position of ambulance services in difficult or distressing terminal care is a generic issue, which should be covered by the recently-published guidance for 'Improving Supportive and Palliative Care for Adults with Cancer'.
Royal College of Speech and Language Therapists	Page 101	Spelling mistake: Tracheostomies	Amended.
Royal College of Speech and Language Therapists	Page 101	No reference is made to nutritional / communication supportive care for palliative patients i.e. access to dietitians & SLT: Regnard, C. Managing dysphagia in advanced cancer – a flow diagram	This is included in the section on Aftercare.

		Palliative Medicine (1990) 4: 215-218 Forbes K (1997). "Palliative care in patients with cancer of the head and neck." Clin Otolaryngol 22(2):117-22	
Royal College of Speech and Language Therapists	Page 103	Patients may also experience problems with communication. We recommend adding communication to first clause so that it reads: 'Most are likely to have problems with eating, drinking and communication'	The sentence in question relates to tube feeding specifically. Communication is discussed further on (and now in more detail) .
Royal College of Speech and Language Therapists	Page 103	It is not clear from the guideline what the evidence base is for the rather sweeping statement: 'These patients often live alone and need a high level of supportive care.'	This was reported by the patient members of the Editorial Board, from their observations and experience, including contact with patient support groups.
Royal College of Speech and Language Therapists	Page 103	We would suggest changing 'this may require specialist help for a year or more' to ' this may require on-going specialist help and support' to more accurately reflect patient's needs	The text has been amended.
Royal College of Speech and Language Therapists	Page 103	Suggest change 'others learn to speak using the oesophagus to 'others use oesophageal voice'	It is felt that this phrase is too technical.
Royal College of Speech and Language Therapists	Page 103/4	It would be useful to have some statistics on why some patients needs are not being met i.e. inadequate funding for posts. (We may be able to assist with this) We aware of centres trying unsuccessfully for additional funding spanning years. This leads to inequities across regions. It needs to be given higher priority.	Required resources to implement the guidance will be covered in the Economic review.
Royal College of Speech and Language Therapists	Page 104	We reconsider the recommendations made for the structure of support and rehabilitation services, and MDTs at Cancer Centres to be excellent, and strongly support them	No comment required.
Royal College of Speech and Language Therapists	Page 105	Spelling mistake: Tracheo-oesophageal	Amendment made.
Royal College of Speech and Language Therapists	Page 105	While we welcome the listing of members for Local Support Teams, we are concerned that the different levels of detail for example ENT nurse practitioner role, might inadvertently indicate a degree of importance over and above other team members which seems to be contradictory to the ethos of multidisciplinary	The detail is included to ensure clarity of the 7 day service required.

		working. Also some of the tasks allocated to the ENT nurse practitioner role fall within the remit of the SLT role, for example management of TEP prostheses.	
Royal College of Speech and Language Therapists	Page 105	We suggest there does need to be better links with primary care. District nurses are not represented. Furthermore, it is a disappointing that social workers receive little mention since financial problems are often high priority on a patient's agenda. We also consider that more emphasis needs to be put on the staff from the specialist centre educating those in the community.	These points are already covered in Structure of Services (topic 2) and are cross-referenced in this section.
Royal College of Speech and Language Therapists	Page 106	There is no mention of access to swallowing assessment, and we strongly recommend this is included. i.e. videofluoroscopy, FEES and nasendoscopy/rigid endoscopic assessments. *Denk et al (1997)* Videoendoscopic biofeedback: a simple method to improve the efficacy of swallowing rehabilitation of patients after head and neck surgery. Otorhinolaryngology 59:100-105 *Wu et al (2000).* Dysphagia after radiotherapy: endoscopic examination of swallowing in patients with nasopharyngeal cancer. Ann Otol Rhinol Laryngol 109(3):320-5 *Logemann JA (1993).* "The diagnostic procedure as a treatment efficacy trial." Clinics in Communication Disorders 3(4):1-10 *Logemann, JA. Pauloski, BR. Rademaker, A. Cook, B. Graner, D. Milianti, F. Beery, Q. Stein, D. Bowman, J. Lazarus, C. (1992*) "Impact of the diagnostic procedure on outcome measures of swallowing rehabilitation in head and neck cancer patients." Dysphagia 7(4) 179-86	Too detailed – these are not clinical guidelines.
Royal College of Speech and Language Therapists	Page 106	We suggest insert 'assessment, techniques etc. so that the sentence begins: 'A full range of assessments, techniques…'	Not accepted.
Royal College of Speech and Language Therapists	Page 106	Suggest insertion of swallowing so that the line reads: '.. available for functional swallowing and voice rehabilitation;..' and insertion of 'but patient choice paramount', after SVR preferred	The comment that SVR is to be preferred has now been deleted.
Royal College	Page	Add 'and other communication aids should be available' after	This is already clear from the text.

of Speech and Language Therapists	106	'electronic larynx equipment' to ensure patients are ale to access a full range of aids for communication and not just artificial larynx	
Royal College of Speech and Language Therapists	Page 106	We would suggest that 'Audit and research' is included when stating the role of the SLT	This is included in the section on the role of the MDT.
Royal College of Speech and Language Therapists		Given the statements on page 76 stating focus groups state that counsellors do not always listen but try to find solutions (see comments above (p76) querying the appropriacy of counselling approaches), it would be interesting to research the counselling approach patients would prefer / preferred, for example a person centred Rogerian approach compared to cognitive – behavioural therapy.	No response required.
Royal College of Speech and Language Therapists	Page 106	Please also see first comment for page 76	No response required.
Royal College of Speech and Language Therapists	Page 107	Where SVR is in place, these patient may be discharged from the full MDT team follow up, but will always require follow up with SLT and occasionally CNS for maintenance of their SVR requirements	Already covered in the text.
Royal College of Speech and Language Therapists	Page 107	We recommend that mention is made of the SLT role in working with patients who have prosthetics for speech & swallowing	Please clarify what this refers to.
Royal College of Speech and Language Therapists	Page108	While we agree with the statements here, the evidence base is unclear. Variability and inequity of patient experience are the problems and some areas have extremely poor services. However some areas have excellent services. Might these services be used for benchmarking? We suggest the first sentence is reworded to convey this.	Text re-worded. This is about benefits, not recommendations.
Royal College of Speech and Language Therapists	Page 108	The section on page 108 states that there is little recent research into rehab effectiveness, please see below for references. A difficulty in producing evidence is that often not enough clinical time, let alone research. RCT are difficult due to the nature of	These references have been considered in the review process, where appropriate.

		individual, combined treatments and small caseloads. It would be very helpful if the guidelines could outline the need for SLT research and that this should be part of the job responsibilities for senior clinicians. This could then be used to secure time to carry out this essential research	There is a generic issue relating to lack of evidence – research is one of the key recommendations.
Royal College of Speech and Language Therapists	References:	We were unsure which articles had been submitted so have listed some pertaining to swallowing therapy. Denk et al (1997) Videoendoscopic biofeedback: a simple method to improve the efficacy of swallowing rehabilitation of patients after head and neck surgery. Otorhinolaryngology 59:100-105 Eisbruch A et al (2002). "Objective assessment of swallowing dysfunction and aspiration after radiation concurrent with chemotherapy for head and neck cancer." Int J Radiat Oncol Biol Phys 53(1):23-8 Kotz, T. Abraham, S. (1999). "Swallowing and tongue function following treatment for oral and oropharyngeal cancer." Journal of Speech Language and Hearing Research 43(4): 1011-1023 Lazarus, C. Logemann, JA. Song, CW. Rademaker, AW. Kahrilas, PJ. (2002) "Effects of voluntary manoeuvres on tongue base function for swallowing." Folia Phoniatrica et Logopaedica 54:171-176 Lazarus CL. (2000). "Management of swallowing disorders in head & neck cancer patients: optimal patterns of care." Semin Speech Lang 21(4):293-309 Lazarus, C. Logemann, JA. Gibbons, P. (1993) "Effects of manoeuvres on swallowing function in a dysphagic oral cancer patient." Head & Neck 15:419-424	All the references used to support the guidance are included in the Research Evidence, available with the second consultation draft of the manual.

		Pauloski B. R., Rademaker A. W., Logemann J. A., and. Colangelo L. A. Speech and swallowing in irradiated and nonirradiated postsurgical oral cancer patients. Otolaryngol Head Neck Surg 118 (5):616-624, 1998. Samlan RA. et al (2002). Swallowing and speech therapy after definitive treatment for laryngeal cancer. Otolaryngologic Clinics of North America 35:1115-1133 Zuydam AC. Et al (2000). "Swallowing rehabilitation after oro-pharyngeal resection for squamous cell carcinoma." Br J Oral Maxillofac Surg 38(5):513-8	
Royal College of Speech and Language Therapists	Page 109	The guideline needs to consider more up to date literature for example laryngectomy voice (Armstrong 01, Perry 03, Frowen – please references at the end of this table list). SVR has transformed laryngectomy rehabilitation in the last 20 yrs. The studies referred to fail to include the large body of evidence that states SVR speech is more intelligible than oesophageal voice and electolarynx speech. Also, patients in studies preferred SVR voice to oesophageal voice in volume and fluency. Using USA studies as a baseline is always flawed because of the differences of their health provision (compared to the NHS) i.e. so cost-based and insurance led, and there are patients in the Head &Neck Cancers population who would not fall within insured categories, and therefore are under represented in these studies. We have mentioned the applicability of Swiss studies. We consider the results from the studies mentioned presented to be of questionable applicability to the UK.	See response above. Reference to the Swiss studies has been removed. This issue is already discussed in the text.
Royal College of Speech and Language Therapists	Page 109 - continued	We recommend RCSLT specialist advisors re write this section and provide up to date references for NICE to consider regarding the key aspects of SVR rehabilitation and the outcomes.	See response to point above.
Royal College of Speech and Language	References	Armstrong, E., Isman, K., Dooley, P., Brine, D., Riley, N., Dentice, R., King, S., & Khanbhai, F. (2001). An investigation into the quality of life of individuals after laryngectomy. *Head Neck, 23*(1),	See response to point above.

Therapists		16-24. Corbridge, R., & Cox, G. (2000). The cost of running a multidisciplinary head and neck oncology service--an audit. *Rev Laryngol Otol Rhinol (Bord), 121*(3), 151-153. de Graeff, A., de Leeuw, J. R., Ros, W. J., Hordijk, G. J., Blijham, G. H., & Winnubst, J. A. (2000). Pretreatment factors predicting quality of life after treatment for head and neck cancer. *Head Neck, 22*(4), 398-407. De Leeuw, J. R., De Graeff, A., Ros, W. J., Hordijk, G. J., Blijham, G. H., & Winnubst, J. A. (2000). Negative and positive influences of social support on depression in patients with head and neck cancer: a prospective study. *Psychooncology, 9*(1), 20-28. de Maddalena, H., & Zenner, H. P. (1991). [Anxiety and coping with anxiety in patients with head and neck cancers]. *Hno, 39*(2), 64-69. del Rio Valeiras, M., Martin Martin, C., Perez-Carro Rios, A., Minguez Beltran, I., Rodriguez Martul, C., Bravo Juega, E., & Labella Caballero, T. (2002). [Possible factors influencing rehabilitation of the total laryngectomy patient using esophageal speech]. *Acta Otorrinolaringol Esp, 53*(6), 413-417. Deshmane, V. H., Parikh, H. K., Pinni, S., Parikh, D. M., & Rao, R. S. (1995), Laryngectomy: a quality of life assessment. *Indian J Cancer, 32*(3), 121-130. Frowen, J., & Perry, A. (2001). Reasons for success or failure in surgical voice restoration after total laryngectomy: an Australian study. *J Laryngol Otol, 115*(5), 393-399. Hammerlid, E., Wirblad, B., Sandin, C., Mercke, C., Edstrom, S., Kaasa, S., Sullivan, M., & Westin, T. (1998). Malnutrition and food intake in relation to quality of life in head and neck cancer patients. *Head Neck, 20*(6), 540-548.	

		Lehmann, W., & Krebs, H. (1991). Interdisciplinary rehabilitation of the laryngectomee. *Recent Results Cancer Res, 121*, 442-449. McKinstry, A., & Perry, A. (2003). Evaluation of speech in people with head and neck cancer: a Pilot Study. *Int J Lang Commun Disord, 38*(1), 31-46. Perry, A. R., & Shaw, M. A. (2000). Evaluation of functional outcomes (speech, swallowing and voice) in patients attending speech pathology after head and neck cancer treatment(s): development of a multi-centre database. *J Laryngol Otol, 114*(8), 605-615.	
Royal College of Speech and Language Therapists	References	Perry, A. R., Shaw, M. A., & Cotton, S. (2003). An evaluation of functional outcomes (speech, swallowing) in patients attending speech pathology after head and neck cancer treatment(s): results and analysis at 12 months post-intervention. *J Laryngol Otol, 117*(5), 368-381. Stafford, N. D., Lewin, R. J., Nash, P., & Hardman, G. F. (2001). Surgeon information giving practices prior to laryngectomy: a national survey. *Ann R Coll Surg Engl, 83*(6), 371-375. van der Donk, J., Levendag, P. C., Kuijpers, A. J., Roest, F. H., Habbema, J. D., Meeuwis, C. A., & Schmitz, P. I. (1995). Patient participation in clinical decision-making for treatment of T3 laryngeal cancer: a comparison of state and process utilities. *J Clin Oncol, 13*(9), 2369-2378.	See response to points above.
Royal College of Surgeons of England			This organisation was approached but did not respond.
Royal Pharmaceutical Society of Great Britain		Thank you for your email dated 30th January. Please note that the Royal Pharmaceutical Society of Great Britain will not be submitting any comments for the above consultation.	This organisation responded and said that it has no comments.
Scarborough and North East			This organisation was approached but did not respond.

Yorkshire Health Care NHS Trust			
Scottish Intercollegiate Guidelines Network (SIGN)			This organisation was approached but did not respond.
Sheffield Teaching Hospitals NHS Trust			This organisation was approached but did not respond.
Society and College of Radiographers	General	The Society & College of Radiographers welcomes the opportunity to comment upon the above draft and would like to offer the following points:	No response required.
Society and College of Radiographers	General	The document is certainly comprehensive and addresses a Cancer site where there is such variation in practice and team set-up across the country, therefore it is welcomed.	No response required.
Society and College of Radiographers	General	Overall the document is pushing for the set up of the MDT with a key role for the Clinical Nurse Specialists as a necessary support for both the patients and the MDT that we support. However it should be borne in mind that equally there are therapy radiographers also able to undertake such a role if they have the requisite competencies	The balance has now been changed in the text, with additional information on roles other than that of the CNS now included. The text on the role of the CNS has also been revised.
Society and College of Radiographers		We feel that a more explicit link with and the access to the therapy radiographer's knowledge during the RT aspects of a patient's treatment and how this information is fed back to the MDT should be included. Clinical practice experience demonstrates the value of therapy radiographers attending MDT meetings to feed back directly, ensuring that relevant information is shared with the MDT and enable information to flow back directly to the RT team managing the patients treatment. Additionally the CNS normally has far too wide a brief to be able to perform this during the RT phase. Additionally therapy radiographers have far more detailed knowledge of the RT planning, delivery and side effects and will see the patient each day for around 6 weeks, during which the care for the patient in	Topic 2, Structure of services, which includes the membership and modus operandi of the MDTs, has been substantially re-structured and re-written. The text on the role of the CNS has been substantially revised.

		terms of managing acute side effects changes quite considerably for these cancers.	
Society and College of Radiographers	Key recommendations	Each MDT SHOULD include CNS- Is this necessary bearing in mind previous comment re skills not profession on Page 4. Is this too prescriptive?	The wording of the key recommendations has been substantially revised.
Society and College of Radiographers	Page 44	Include radiographer? Particularly because of specialist needs of head and neck patients undergoing radiotherapy. This has been shown to be of particular benefit in a regional centre with many tertiary clinics – Ref Keane ESTRO abstract S64 161 2003.	Treatment radiographers are important, and their role is recognised in para 3 of the section on support for patients undergoing radiotherapy (changing a little in the next version).
Society and College of Radiographers	Page 82	The importance of mouth care and oral hygiene during RT is imperative not 'must be emphasised' – pts must see dental hygienist, oral care during RT. Additionally support for the patients must be underpinned by appropriately educated and skilled staff that in turn receive support from the wider MDT.	This is a matter of linguistic style. As far as the developer is concerned this point has been given considerable emphasis with a clear recommendation in the guidance. More emphatic language disturbs the balance of the entire document and is not consistent with previous IOG publications.
Society and College of Radiographers	Pg.82	In patient facilities need to be available and wards must have specialist staff to care for these patients needs?	It has not been our practice to describe hospital facilities in general terms unless there is a specific issue relevant to the provision of this patient group. This does not apply in this case. It can be assumed that any specialist radiotherapy facility will have beds capable of managing the range of radiotherapy patients managed for that unit. We have, however, specified the sorts of expertise particular to head and neck patients that are needed, whether on an in-patient or an out-patient basis.
Society and College of Radiographers	Page 86	We believe this should read as follows; 'The most important cause of interrupted treatment was machine downtime either planned servicing or to deal with machine breakdown'	The revised phraseology is accepted and this sentence has replaced the current text.
Society and College of Radiographers	Page 93	Availability of specialist wards for patients undergoing surgery and RT are required.	The main recommendation concerns specialist wards for surgery. In specialist radiotherapy facilities the case for specialist wards has not led to a recommendation.
Society and College of Radiographers	Page 92	In centres offering Brachytherapy, specialist facilities are required with appropriately trained and educated staff.	No comment required.
Society for Endocrinology		Our comments are confined to the management of patients with thyroid cancer. This represents the commonest endocrine malignancy but is a rare diagnosis, compared with the very high	The text has been changed in a number of places to improve clarity.

		population prevalence of benign nodular thyroid disease and of thyroid dysfunction, which in itself is often associated with goitre. It is noted in the draft (page10) that thyroid cancer is totally unlike other cancers. While it is entirely appropriate that thyroid cancer is included in this guidance document, improved clarity, especially in terms of referral patterns and MDTs, is required. This is especially important given the population prevalence of benign thyroid disease and the fact that much of the burden of investigation of this disease is at DGH level.	
Society for Endocrinology	Page 22	It should be noted that small thyroid cancers (usually papillary) are sometimes found 'incidentally' if thyroid surgery is performed for reasons other than known or suspected thyroid cancer.	Too much detail for the Background section.
Society for Endocrinology	Page 25	Should read 'a history of radiation exposure'	Agreed. Amendment made.
Society for Endocrinology	Page 27	It may be helpful to present a more contemporary picture of how thyroid cancer is managed surgically. This section might state 'Thyroid cancer may be treated surgically by endocrine surgeons or Head and neck surgeons." There should be a nominated thyroid cancer surgeon for each region/large district.	The text referred to has now been revised.
Society for Endocrinology	Page 30	The statement that there should be specific referral routes for all patients with neck lumps or thyroid nodules (considered together) is confusing. The guideline document should be clear that it refers primarily to patients with known thyroid cancer. It is desirable that each hospital does indeed have a specific referral route for thyroid nodules (e.g. to a thyroid surgeon or endocrinologist) with an onward referral pathway when the diagnosis of thyroid cancer has been made.	This refers to all patients with symptoms; cancer may not be suspected at this point.
Society for Endocrinology	Page 31 –32	Unresolving neck masses for >3 weeks. It should be made clear that this statement does not refer to thyroid lumps (which are typically present for months or even years before referral).	The urgent referral criteria are taken verbatim from the DH criteria. These are currently being revised by NICE.
Society for Endocrinology	Page 32	Not all district general hospitals investigating thyroid nodules with FNAC have an on-site thyroid cytopatholgist. Easy and prompt access to such expertise 'off-site' may be appropriate	Agreed. The issue is about moving towards provision of this expertise. The new draft acknowledges that this may take some time to achieve, and that interim arrangements may be necessary.
Society for Endocrinology	Page 33	It is not clear that all patients with thyroid lumps over 65 years require urgent referral. This statement might be omitted or	The reference from which this list is derived is given in the text.

		qualified by the statement ' new or rapidly enlarging'.	
Society for Endocrinology	Page 38	The data cited re thyroid patients are incomplete (no info re diagnosis, outcome etc) and therefore seem unhelpful.	This information has been added.
Society for Endocrinology	Page 41	As stated elsewhere, the structure of MDTS dealing with thyroid cancer is often different to that for other UATs; even the largest regional centre is unlikely to see 100 new cases of thyroid cancer annually.	This has been clarified; the thyroid cancer MDT serves a population base in excess of a million. Reference to new cases is not made.
Society for Endocrinology	Page 42	It is felt strongly that the statement that MDTS should manage both benign and malignant thyroid disorders is inappropriate. While clinicians managing benign thyroid disease (e.g. endocrinologists, thyroid surgeons) will sometimes be part of a regional thyroid cancer MDT, this is often not the case. Core members of the MDT for thyroid cancer should comprise thyroid surgeon, endocrinologist and clinical oncologist (see BTA guidelines).	This was not the view of the Editorial Board. No amendment proposed.
Society for Endocrinology	Page 57	Reference 68 is not cited properly. Same citation required p91	Ref 68 is a footnote, explaining the importance of thyroglobulin; please clarify.
Society for Endocrinology	Page 61	Sentences 3 and 4 from end of page (starting thyroid cancer may be suspected..) should be omitted and replaced with: 'All patients presenting with thyroid cancer/nodules should have a test of thyroid function. Once overt thyroid dysfunction has been excluded patients should have FNAC performed'.	Agreed, this amendment has been made. Text now reads: 'All patients who present with thyroid nodules should have tests of thyroid function. When overt thyroid dysfunction has been excluded, FNAC should be performed.'
Society for Endocrinology	Page 64	This section should emphasise the overwhelming evidence for sensitivity of FNAC when used as first line investigation is suspected thyroid cancer. It should also emphasise the lack of advantage of core biopsy compared with FNAC, but greater morbidity. This section should emphasise the lack of evidence, at the present time, to support the routine use of ultrasound imaging, either to aid the diagnosis of thyroid cancer, or to guide FNAC.	The recommendations are consistent with this comment. The fuller evidence picture is contained within the Research Evidence
Society for Endocrinology	Page 107	Last sentence should read 'Thyroid function tests, serum calcium, thyroglobulin or calcitonin should be monitored regularly'	The text has been re-drafted to improve clarity.
Society of British Neurological			This organisation was approached but did not respond.

Surgeons			
Teenage Cancer Trust, The			This organisation was approached but did not respond.
Tenovus Cancer Information Centre			This organisation was approached but did not respond.
The Royal College of Physicians	Page 83	This paragraph implies that Radioiodine facilities and expertise are only available at cancer centres. This is not so and indeed not only do some large DGHs have these facilities eg Medway Hospital and Kent and Canterbury Hospital, but also not all cancer centres have these facilities.	We have revised the text of paragraph 3 of Thyroid Cancer so that it ends as follows: 'Is likely to require expertise and facilities which are only available on a limited number of hospital sites, mainly in Cancer Centres'.
The Royal College of Physicians	Page 86-87	It should be made clear that the radiotherapy does not play a routine role in the management of thyroid cancer and chemotherapy plays no role.	The current four paragraphs on the treatments of thyroid cancer make clear that radiotherapy has only limited and specific roles, and chemotherapy is not mentioned.
The Royal Society of Medicine			This organisation was approached but did not respond.
Trent Strategic Health Authority			This organisation was approached but did not respond.
UK Pain Society			This organisation was approached but did not respond.
Walton Centre for Neurology and Neurosurgery NHS Trust			This organisation was approached but did not respond.
Welsh Assembly Government (formerly National Assembly for Wales) And	General	We suggest that a central MDT meeting attended by all current clinicians in one site to discuss new/recurrent/difficult cases with follow up and treatment at peripheral centres in most cases may be a suitable network model.	Topic 2, structure of services, which describes the MDTs and how they should function, has been re-drafted.

Cancer Services Co-ordinating Group			
Welsh Assembly Government	General	There is a lack of personnel in some networks especially pathologists, radiologists, palliative medicine physicians SALT etc. The best use of scarce specialist resources are a strong determinant for having fewer, but better resourced, MDTs serving a population. We suggest that this could have more emphasis.	See response to point 1 about the functioning of the MDT. The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation.
Welsh Assembly Government	General	There are frequent references to the effects of head and neck cancer on speech/swallowing but little reference to resource implications for speech and language therapy – in contrast to the CNS.	The resource issues covered by the economic review are discussed in the draft economic review, available for the second consultation. Additional information on the role of the SLT is also included.
Welsh Assembly Government	General	Where document mentions CNS, this is a very specific role. Even though some Trusts do have such nurses, not all do. Oncology Nurse Specialists are often part of the team and support patients and their families from the oncology side. We feel that this has not been addressed, maybe because ONSs are only employed in specific regions.	The text on the role of the CNS has now been considerably revised.
Welsh Assembly Government	Pg.8	Key Recommendations 3rd point – "speech, language and swallowing services" – we are unclear whether this refers to Speech and language therapy plus other services involved with swallowing? If so, we suggest it should read "Speech and language therapy and swallowing services"	The wording of the key recommendations has been substantially revised.
Welsh Assembly Government	Pg.41	Management by Multidisciplinary Teams Footnote 58 – "BAHNO guidelines recommend that MDTs should deal with a minimum of 80 new cases per year. This is regarded as a conservative figure which might be appropriate for MDTs serving sparsely populated areas such as parts of Wales". There is a lack of consistency between this and other published NICE Guidance, which does not make reference to specific population bases for Wales. We suggest that the guidance should be more consistent in this respect.	Wales was merely given as an example of sparsely populated areas, and has now been deleted.
Welsh Assembly	Pg.43-46	Members of the head and neck cancer MDT The guidance states that every speciality should be represented	The skills should always be covered. This will depend on local circumstances and arrangements (i.e. the network

Government		at each meeting, that cover should always be available and all members of the core team should specialise in head and neck cancer. This would require two "specialists" per discipline, but we have received concerns that this is not reflected in the list of core members, which implies that only one Speech and language therapist and one Dietitian is required. (There are resource implications for such small disciplines and this needs to be shown). Supporting and advising other, and offering an outreach service also has resource implications as does providing a local service (p.105).	responsibility). The economic review will be available with the second draft.
Welsh Assembly Government	Pg.46	The Clinical Nurse Specialist "A named Head & Neck CNS should be available to support every patient, throughout the course of their disease". We suggest this may be more user focused if "should the patient or family require" was added.	Not accepted. This is implied by 'available'.
Welsh Assembly Government	Pg.48	The Speech and Language Therapist The final sentence – 2nd paragraph – refers to face to face communication. However, SALTs deal with communication as a whole (including introducing communication aids). We suggest that this should state "eating, drinking and communication".	This phrase has been removed from here.
Welsh Assembly Government	Pg.51	Anticipated Benefits We have received objections to the statement regarding the role of the palliative medicine physician in taking the emotional strain off other members of the MDT.	This has now been re-worded.
Welsh Assembly Government	Pg.51	Achieving consistency within networks We suggest that Pathology proforma dataset reports should be introduced across the network.	This is within the remit of the local networks.
Welsh Assembly Government	Pg.55	Centralisation We have some concerns about the resource implications and lack of proof for better outcome.	The Economic Review will be available at the web consultation.
Welsh Assembly Government	Pg.57	Thyroid We have concerns that there are too many surgeons doing too few operations with inadequate knowledge of thyroid cancer management and follow up.	The purpose of the guidance is to rectify this.
Welsh Assembly Government	Pg.58	Measurement – Process "Evidence that every patient is interviewed by a CNS.." The situation may arise where patient may not want to be interviewed.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that

		We suggest that this is included in the criteria.	all patients should be assessed by a CNS, and this measure should stand.
Welsh Assembly Government	Pg.62	We suggest that all thyroid cancers diagnosed on FNAC or biopsy should be referred to MDT thyroid surgeon pre-thyroidectomy and all cases should be discussed by MDT meeting.	This point is adequately covered in para 3.
Welsh Assembly Government	Pg.62	Informing Patients It may not be possible for CNS to be at every consultation where bad news is broken. We suggest that a trained member of clinic staff could support and then liase with CNS giving details of new patient and diagnosis, and give CNS contact details out to patient.	This has been extensively discussed by the Editorial Board. The text on the role of the CNS has been revised for the new draft; however, the recommendation is that all patients are assessed by a CNS.
Welsh Assembly Government	Pg.63 - 64	User Support – last paragraph We suggest this may need clarification as it could be interpreted as saying only those with experience of laryngectomy should be matched with newly diagnosed patients. It needs to be clarified as a need for all newly diagnosed people with a head and neck cancer.	No amendment proposed; this inference from the text as written is not accepted.
Welsh Assembly Government	Pg.63	Final Paragraph The speech and language therapist should ideally facilitate the mechanism referred to, as this is a significant part of the SALTs role. We have concerns that the wording is misleading, and suggest changing to "who have been trained in supporting newly-diagnosed patients (by a speech and language therapist, CNS, or psychologist)	Agreed. This amendment to the wording is accepted. The text has now been changed in response to other comments, to read as follows: 'There should be a defined mechanism, facilitated by a CNS or SLT, to ensure that patients who are likely to be offered radical treatment are given the option of introduction to others who have been through similar experiences and who are able to offer support to newly-diagnosed patients. Training (for example, 'CancerVoices' training provided by Macmillan Cancer Relief) should be arranged for these patient visitors.'
Welsh Assembly Government	Pg.71	2nd paragraph, final sentence "restore speech". We have concerns that this is misleading, and suggest that it should read "to facilitate communication and swallowing".	The current draft now reads as follows: 'The SLT…will work with the patient to make the most of his or her potential for recovery of speech, voice and swallowing.'
Welsh Assembly Government	Pg.76	Preparation for laryngectomy Although reporting on a study and the interviewees' suggestions, we have concerns that "speech training conducted by laryngectomees" is open to misinterpretation, and devalues the	This point is very similar to that made by others and has been accepted in the re-drafting of the text.

		SALTs role. Furthermore "speech training" is carried out post-operatively. We are unclear whether this is referring to pre-operative opportunity to speak to a rehabilitated laryngectomee – as per following paragraph? (Generally SALTs involve rehabilitated laryngectomees pre and post operatively).	
Welsh Assembly Government	Pg.81	First Sentence We suggest this should include specialist SALT support on wards.	Agreed. This is now included.
Welsh Assembly Government	Pg.82	Support for patients undergoing radiotherapy "Patients should have access to a specialist oncology dietitian and speech and language therapist – we suggest "specialist" speech and language therapist.	There is an inconsistency in terminology here. The reference to speech therapists is now speech and language therapists.
Welsh Assembly Government	Page 89	Patients' views on hospital services This is one of the most important factors in aiding recovery, both physical and psychological, especially for patients who have undergone radical surgery to face. Some patients who have been, in the first instance, profoundly disfigured by their surgery (albeit a life saving measure) are expected to cope with the incredulous stares of the stream of visitors that pass through a public ward. It's perfectly reasonable that disfigurement becomes almost normalised to staff as they are dealing with it every day, but this is not so for the patient. At times like these, affording the patient their privacy and dignity can make all the difference.	The text has been revised to include the following paragraph: 'Hospital staff, particularly ward staff, should be alert to these patients' psychosocial needs and should take appropriate action to meet such needs as far as this is possible. Staff must be aware of the importance to patient of maintaining their dignity despite the disfiguring effects of surgery. Some patients do not wish to be seen by members of the public and should be given privacy, if this is what they prefer, during ward visiting times.'
Welsh Assembly Government	Pg.92	Measurement – Structure Refers to a "speech, language and swallowing therapist" – swallowing is part of the SALTs role. We suggest this should state "suitably specialised and experienced dietitian and speech and language therapist".	Response already made to this point – this is a duplicate.
Welsh Assembly Government	Section 5	We suggest this recommendation should include easy access to funding for communication aids/equipment, as required for individual patients. Currently this is a time consuming and unsuccessful process.	This appears to be an important point. However it doesn't fit well with the nature of Topic 5 which is dealing with the primary treatment modalities themselves, rather than with the supportive and care aspects. An

			appropriate inclusion has been made in the restructured Topic 6, Aftercare, rehabilitation and support.
Welsh Assembly Government	Pg.100	First paragraph - "Choking or bleeding to death is particularly feared…" We suggest that 'Guidelines on a Carotid Blowout and Tracheal Airway Obstruction' produced by BAHNON (British Assoc. of Head & Neck Oncology Nurses) should be included for reference.	Should be covered in local protocols.
Wessex Cancer Trust			This organisation was approached but did not respond.
Wyeth Laboratories			This organisation was approached but did not respond.